

PASTORAL CARE OF THE TERMINALLY ILL  
PATIENT AND THE FAMILY

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A Dissertation  
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School of Theology at Claremont

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In Partial Fulfillment  
of the Requirements for the Degree  
Doctor of Philosophy

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by  
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June, 1975

*This dissertation, written by*

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IN MEMORY OF

Elmine Venter, whose death taught me early in my life what separation and loneliness really mean.

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For      Antoinette

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## ABSTRACT

### PASTORAL CARE OF THE TERMINALLY ILL PATIENT AND THE FAMILY

Problem: With the advance in modern medicine and modern medical technology extended dying, over months or even years, is now much more common than it was several decades ago. For many individuals, advances in the diagnosis and the treatment of illness have postponed death, but at the cost of extending the process of dying and subsequently the emotional trauma for everyone involved.

Society has developed hospitals and other institutions to keep up with the rapid development in modern medical science and to handle the death experience, but society has failed in helping people cope with terminal illness and the church is a participant in this failure!

The pastor as representative of the church in the modern hospital is "uncomfortable" in the presence of death, working with the terminally ill patient. The result is that terminally ill patients and their families become gradually more and more neglected by the pastor and the church.

Purpose: Therefore, it is proposed to study the psychology and needs of terminally ill children, terminally ill adults and their families and to illuminate the pastoral role of the clergy and the church.

Hypothesis: At the moment when a patient becomes terminally ill, the pastor is in a unique position to move beyond the other members of the caring team who often have done their best, to restore life, but have

lost the battle. The pastor can join forces with the patient and the family to help them grow; to help them discover themselves, their neighbor, their God.

Methodology: The method proposed for the study is an exploratory analysis and evaluation of

1. The insights regarding the problem from the literature in this area of study,
2. my own experience at St. Christopher's Hospice in London, England where I worked with and studied terminally ill patients,
3. my visit to The Netherlands where I looked for different insights and methods in working with terminally ill patients,
4. my experience with terminally ill patients as Hospital chaplain in different hospitals over the past five years.

Conclusion: The hypothesis has been confirmed by this study. The pastor, as member of the medical team, having worked through his/her own feelings about death and dying can help the terminally ill patient increase the ability to affirm his/her life in the face of his/her limitations, because he/she is rooted and grounded in the source and sustainer of life, namely God.

The possibility for growth in a terminally ill patient increases in a therapeutic community like St. Christopher's in London.



**PART I**

**PERSPECTIVE**

## CHAPTER 1

### INTRODUCTION

#### 1.1 The Problem of the Dissertation

Extended dying, over months or even years, is now much more common than it was several decades ago. With the advance in modern medicine and modern medical technology, a terminally ill patient may survive for a long time. A child, badly crippled and disfigured by an accident may survive with expert medical and surgical care only to die more gradually over a longer period of time.

An elderly person with a malignant tumor may now be kept alive for many more weeks by the use of intensive medical palliative procedures and by multiple surgical interventions.

For many, many individuals, advances in the diagnosis and the treatment of the illness have postponed death, but at the cost of extending the process of dying and subsequently the emotional trauma for everyone involved. This brought about an increase in terminally ill patients in our hospitals, where the majority of Americans die in our time.

A death in a family is almost always a traumatic experience, but there is no more devastating experience in the life of a family than the fatal illness of a child. The family members are confronted with a crisis in coping with loss and grief. The shock extends from parents and siblings to involve grandparents, other families and

friends. All the pain and the grief and the suffering are exaggerated by a long, lingering, terminal illness.

Because of the developments in modern medical science, modern chemotherapeutic agents, improvements in living conditions, death is increasingly the experience of the elderly and it happens in hospitals and institutions. Child mortality declined sharply and the death of a child has become a rare event. This may be a reason why it is more difficult for parents or for spouses in their midyears and younger to accept the diagnosis of terminal illness in a child or in each other.

Society has developed hospitals and other institutions to keep up with the rapid development in modern medical science, but society has failed in helping people cope with the terminal period and the Church is a participant in this failure!

The terminally ill patient can not and may not be seen and cared for as a separate entity, apart from the family. There is a unity, a natural harmony between patient and family and it must be safeguarded as long as possible in order to allow the patient and the family to grow and mature during this period of terminal illness.

In spite of all the emphasis on death and dying and on the needs of the terminally ill patient, since Elizabeth Kübler-Ross first published her book "On Death and Dying"<sup>1</sup> in 1969; In spite of all the workshops and seminars on death and dying there is still a

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<sup>1</sup>Elizabeth Kübler-Ross, On Death and Dying (New York: Macmillan, 1969).

feeling of discomfort amongst pastors when in the presence of death, working with the terminally ill patient. This discomfort may be related to feelings of ambivalence, to uncertainty as to the place, the task and the responsibilities of the pastor in the comprehensive care of the terminally ill; to fear to intrude upon the domain of the physician, the social worker, the nurse; to feelings of being an adjunct to the medical team and not an integral part of the healing profession; to experiencing existential anxiety; anxiety about death and dying itself.

The result is that terminally ill patients become gradually more and more neglected by the pastor and the church. (This is in correspondence with the general trend in our modern hospitals to gradually isolate and reject the terminally ill patient.) In the case of terminally ill children the neglect is even worse!

The pastoral care of the families of a terminally ill adult or a terminally ill child is just as neglected as the comprehensive care of the patient and her/his family in the modern hospital!

Studies indicate a significant difference in mortality among surviving spouses according to whether the death has taken place at home or in a hospital.<sup>2</sup> The risk of the nearest relative dying within a year of bereavement was found to be twice as great if the death had occurred in the hospital rather than the home. Studies also show a 50% increase in behavior problems among well siblings of

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<sup>2</sup>W. Rees et al. "Mortality of Bereavement," British Medical Journal (Oct. 7, 1967).

a terminally ill child.<sup>3</sup> These facts become a terrible accusation against the health care professions and as such, against the Church!

My thesis is that when the patient becomes terminal, this is exactly the moment when the pastor can move beyond the other members of the team who often have done their best, to restore life, but lost the battle. Before and especially during the terminal phase the pastor can join forces with the patient and the family; helping them grow to fulfillment, helping them finish unfinished business; helping the patient to loosen her/himself from life and this world and die a dignified death; helping the family in their anticipatory grief and in their bereavement. A passive fearful pastor cannot do this!

In this dissertation I will investigate the belief that every human being has the God-given human potential, the ability to grow and to mature until death finally comes. It is the pastor's privilege, task and responsibility to help the terminal patient discover more of her/his still latent potential; to discover more of his/her strengths and abilities; to discover more of him/herself, to discover more of his/her neighbor; to discover more of her/his God and to grow into a new relationship with her/his own self, neighbor and God; To grow until she/he dies!

I believe that every human being, even in the terminal phase, has the profound inner striving toward fulfillment, the pull of a better future toward which she/he can move by the fuller use of

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<sup>3</sup>C.M. Binger et al. "Childhood Leukemia," New England Journal of Medicine, CCLXXX (February, 1969), 416.

his/her inner riches.<sup>4</sup> Even in the presence of death can the pastor help the patient discover "the treasure of eternal possibility and the task of unearthing it."<sup>5</sup>

## 1.2 Definitions

Terminal illness: Operationally I shall define terminal illness as a disease state whose presence raises in the mind of the physician, patient and/or family an expectation of death as a direct consequence of the illness.<sup>6</sup>

Terminal care: Terminal care is the care given to a patient from the moment when any further treatment does not offer any hope of healing or recuperation and death becomes inevitable within the foreseeable future. A patient in this situation is terminally ill.

## 1.3 The Method and Plan of the Study

The method proposed for the study is an exploratory analysis and evaluation of

1. The insights regarding the problem from the literature in this area of study,
2. my own experience at St. Christopher's Hospice in London, England where I worked with and studied terminally ill patients.

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<sup>4</sup>Howard J. Clinebell, Jr., Class notes.

<sup>5</sup>Martin Buber, Between Man and Man (Boston: Beacon Press, 1955), p. 84.

<sup>6</sup>Louis Lasagna, "The Prognosis of Death," in Orville G. Brim, et al., The Dying Patient (New York: Russel Sage Foundation, 1970), p. 67.

3. my visit to The Netherlands where I looked for different insights and methods in working with terminally ill patients,
4. my experience with terminally ill patients as Hospital chaplain in different hospitals over the past five years.

Part One will provide a perspective for the study. The problem will be delineated, the literature will be briefly surveyed, using literature from the different disciplines (medicine, sociology, psychology and nursing). Attention will be given to the problems created by the tabu on death and how pastoral care of the terminally ill patient is influenced by it. The impact of the place of dying on pastoral care, problems created, and ways to deal with it will be discussed. In the final section I will look briefly at the Old and New Testament resources to see what the Bible has to say about death and dying and how this is relevant to pastoral care.

In Part Two I will focus on the terminally ill child and the terminally ill adult and the family involved. The major emphasis will be on pastoral care.

In Part Three I will discuss a therapeutic approach to dying and I will translate this into a modern hospital emphasizing the role of the pastor and the congregation. Attention will be given to the spiritual growth of the terminally ill patient.

#### 1.4 Previous Studies In This Field

Interest in the subject of death and dying has been growing, particularly during the past few years. Evidence of this can be found in the exponential increase in the number of books and articles that have recently been published. It was possible to assemble a

bibliography of approximately 400 items in 1964. In 1973 there were more than 2600 items<sup>7</sup> and this trend continued throughout 1974 until the present.

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<sup>7</sup>Robert L. Fulton, Death, Grief and Bereavement—Bibliography 1845-1973 (Minneapolis: University of Minnesota, 1973)



## CHAPTER 2

### SURVEY OF THE LITERATURE

A survey of the literature on death and dying reveals that the topic of death and dying had been sadly neglected, if not avoided by the mental health professions. Until about 15 years ago only a conservative number of publications existed. In the 1960s a new movement in the health care professions started to devote more attention to death and dying and the effect on the dying person and society.

One of the first major contributions to this field was by Alfred Worcester in 1935.<sup>1</sup> Even today, his book is relevant and worth reading. Major contributions to the field of death and dying were made by Eissler (1957),<sup>2</sup> Herman Feifel (1959),<sup>3</sup> Margaretta Bowers

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<sup>1</sup>Alfred Worcester, Care of the Aged, Dying and the Dead (Springfield, IL: Thomas, 1st ed. 1935, 2d ed. 1940)

<sup>2</sup>Kurt P. Eissler, The Psychiatrist and the Dying Patient (New York: International Universities Press, 1973)

<sup>3</sup>Herman Feifel (ed.) The Meaning of Death (New York: McGraw-Hill, 1965)

et al. (1964),<sup>4</sup> Robert Fulton (1965),<sup>5</sup> Glaser and Strauss (1965),<sup>6</sup> and Jeanne Quint (1967).<sup>7</sup>

A major change came after 1969 when Elizabeth Kübler-Ross published her book "On Death and Dying."<sup>8</sup> With new enthusiasm the field was surveyed and studied. Terminally ill patients and their families and the medical team became the object of intensive research. The flow of publications increased drastically with the result that it became almost impossible for a serious student in Thanatology to keep up with the latest publications.

The pastoral care of the terminally ill patient and the family has always been an important part of the ministry of the pastor. I was struck by the relatively few publications by ministers in the area of death and dying. Robert Fulton<sup>9</sup> believes this is due to the fact that ministers in the United States (and this is probably true everywhere in the Western world) kept themselves busy with and involved in social issues—poverty, racial discrimination, the war in

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<sup>4</sup>Margaretta K. Bowers, et al. Counseling the Dying (New York: Nelson, 1964)

<sup>5</sup>Robert L. Fulton (ed.) Death and Identity (New York: Wiley, 1965)

<sup>6</sup>Barney G. Glaser and Anselm L. Strauss, Awareness of Dying (Chicago: Aldine, 1965)

<sup>7</sup>Jeanne C. Quint, The Nurse and the Dying Patient (New York: Macmillan, 1967)

<sup>8</sup>Elizabeth Kübler-Ross, On Death and Dying (New York: Macmillan, 1969)

<sup>9</sup>Personal Conversation with Robert L. Fulton, Center for Death Education and Research, University of Minnesota.

Vietnam, ecology, etc. Their ministry became a ministry to the living. In the course of daily events they came in contact with the terminally ill, but they did not get involved. They removed themselves from death and dying by using rituals, theological language and prayer books. This, of course, is also influenced by the culture in which they lived, which placed a label on the topic of death and dying.

Significant work was done by Clergy on Grief and Bereavement; dealing with the living, the survivors. In the specific area of pastoral care to the terminally ill patient I found a number of articles and a few books written by Autton,<sup>10</sup> Berger,<sup>11</sup> Bowers et al.,<sup>12</sup> and Scherzer.<sup>13</sup> In general, the literature in this area was very disappointing.

It is important for the pastor who wants to deal with death and dying to reflect on Biblical thinking about death and afterlife from the Old Testament times until today.<sup>14</sup> Milton McC. Gatch<sup>15</sup>

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<sup>10</sup>Norman Autton, The Pastoral Care of the Dying (London: S.P.C.K., 1969)

<sup>11</sup>William Berger, De Laaste Levensfase (Bilthoven: Ambo, 1973), III.

<sup>12</sup>Margaretta K. Bowers, et al. Counseling the Dying (New York: Nelson, 1964)

<sup>13</sup>Carl J. Scherzer, Ministering To the Dying (Philadelphia: Fortress Press, 1968)

<sup>14</sup>Milton McC. Gatch, Death (New York: Seabury Press, 1969)

<sup>15</sup>Milton McC. Gatch, "Some Theological Reflections on Death from the Early Church Through the Reformation" in Liston O. Mills (ed.) Perspectives on Death (New York: Abingdon Press, 1969), pp. 99 ff.

traces theological reflections on death from the early days in the Christian Church through the Reformation, and describes how the idea of the resurrection gave way to the concept of immortality in Christian dogma. Lepp<sup>16</sup> presents a psychological approach that deals with both death and afterlife. The meaning of death from a Biblical point of view is considered by Häring,<sup>17</sup> Miller,<sup>18</sup> Choron,<sup>19</sup> Velema,<sup>20</sup> Roscam Abbing.<sup>21</sup>

Abbing deals with two important questions: May a Christian long for death? May the Christian pray for death to come soon? Holden<sup>22</sup> re-examines the teaching of Jesus as well as the Gospels and Epistles concerning the concept of death.

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<sup>16</sup>Ignace Lepp, Death and its Mysteries (New York: Macmillan, 1968)

<sup>17</sup>Bernard Häring, Medical Ethics (Notre Dame: Fides, 1973), pp. 120 ff.

<sup>18</sup>Randolph Crump Miller, Live Until You Die (Philadelphia: Pilgrim Press, 1973), pp. 95 ff.

<sup>19</sup>Jacques Choron, Death and Western Thought (New York: Collier Books, 1973), pp. 81 ff.

<sup>20</sup>W.H. Velema, Rondom Het Levenseinde (Kampen: Kok, 1971), pp. 16 ff.

<sup>21</sup>P.J. Roscam Abbing, Toegenomen Verantwoordelijkheid (Nijkerk: Callenbach, 1972), pp. 26 ff.

<sup>22</sup>Douglas T. Holden, Death Shall Have No Dominion (St. Louis: Bethany Press, 1971)

American society treats death as a tabu subject in order to avoid dealing with the universal fear of death.<sup>23,24</sup> The denial of death may be due to what people observe about dying, the way the terminally ill are taken from homes to die in isolation in big modern hospitals.<sup>25</sup> Many people do not even want to think about death,<sup>26</sup> with the result that they also don't talk about it. Many parents do not discuss death at all with their children.<sup>27</sup> If they have to talk about it, the language is "softened." "Undertaker" becomes "funeral director" or "mortician," "coffins" are "caskets," "graveyard" becomes "Memorial Park," etc.<sup>28</sup> Psychological, cultural and religious theological reasons are given for the existence of the tabu.<sup>29</sup> Evidence of the tabu is found everywhere in modern society,

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<sup>23</sup>H. Feifel, "Death," in Norman L. Faberow (ed.) Taboo Topics (New York: Atherton Press, 1963), pp. 8-21.

<sup>24</sup>G. Gorer, Death, Grief and Mourning (New York: Anchor Books, 1965)

<sup>25</sup>Adriaan Verwoerdt, Communication with the Fatally Ill (Springfield, IL: Thomas, 1966)

<sup>26</sup>Donald Beatty, "Shall We Talk About Death?" Pastoral Psychology, VI (February 1955)

<sup>27</sup>Earl Grollman, Suicide (Boston: Beacon Press, 1971)

<sup>28</sup>Jessica Mitford, The American Way of Death (New York: Simon and Schuster, 1963)

<sup>29</sup>Richard W. Doss, The Last Enemy (New York: Harper & Row, 1974), pp. 4-8.

in the church<sup>30</sup> and in the hospital.<sup>31</sup>

There is a significant change in the attitude about death and dying. Young people and students are being confronted with the reality of death, and are more open about it,<sup>32,33</sup> especially as they hear news of the Vietnam war.

If one is really to understand and comprehend what is going on in the mind of the terminally ill patient one has to look at the places society has created for the terminally ill patient to die in. The majority of terminally ill patients in the United States die in a modern hospital. The modern hospital is a highly specialized, very impersonal place, where people are treated as objects and are dehumanized. The emphasis is on healing and dying is seen as a failure,

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<sup>30</sup>P.J.G. Janssen, "Het Bijstaan van Stervenden" (Unpublished Ph.D. Dissertation, R.C. University, Nijmegen, 1970).

<sup>31</sup>Kübler-Ross, On Death and Dying.

<sup>32</sup>Robert E. Kavanaugh, Facing Death (Baltimore: Penguin Books, 1974)

<sup>33</sup>Eleanor E. Drummond, "Communication and Comfort for the Dying Patient," Nursing Clinics of North America, V:1 (1971), 55 ff.

not only for modern technology, but for the medical team.<sup>34;35;36;37;38</sup>

To cater to the increase in the number of elderly people, nursing homes for the elderly were established where thousands and thousands of elderly people spend their final years and eventually die. Some of the homes are excellent, specially designed to care for the elderly person who becomes terminally ill. Others are overcrowded, poorly maintained and containing many elderly dying people in gloomy dilapidated buildings with discontented staff.<sup>39</sup>

Most people prefer to die at home.<sup>40</sup> However, many patients find it very difficult to adjust to the home situation after a prolonged period of hospitalization.<sup>41</sup> Those who do adjust, usually

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<sup>34</sup>Anna Baziak, "The Language of the Hospital and Its Effect on the Patient," in James K. Skipper (ed.) Social Interaction and Patient Care (Philadelphia: Lippincot, 1965), p. 272.

<sup>35</sup>Heije Faber, Pastoral Care in the Modern Hospital (Philadelphia: Westminster Press, 1971)

<sup>36</sup>Melvin J. Krant and Alan Sheldon, "The Dying Patient—Medicine's Responsibility," Journal of Thanatology, I:1 (February 1971), 5.

<sup>37</sup>Barney G. Glaser and Anselm L. Strauss, Time for Dying (Chicago: Aldine, 1974), p. 191.

<sup>38</sup>"Thanatology Looks at the Doctor and the Dying Patient," Medical World News (May 21, 1971), 30.

<sup>39</sup>John Hinton, Dying (Baltimore: Penguin Books, 1974), pp. 149 ff.

<sup>40</sup>Robert L. Fulton, "Death and Dying: Some Sociologic Aspects of Terminal Care," Modern Medicine, XL (May 29, 1972), 75.

<sup>41</sup>Minna Field, Patients Are People (New York: Columbia University Press, 1967), pp. 124-130.

die at peace, having finished unfinished business, surrounded by kin.<sup>42</sup>

## 2.1 The Terminally Ill Child and the Family

It is necessary to understand the development of the child's concept of death before we can adequately minister to his/her needs.<sup>43;44;45;46</sup>

Extended dying, over months or years, is now much more common in childhood than it was several decades ago because of expert medical and surgical care. Hospitalization is a traumatic experience for most children,<sup>47;48;49</sup> and the situation deteriorates when the

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<sup>42</sup>Elizabeth R. Prichard, "Planning for the Terminally Ill Patient: The Social Worker's Responsibility," Journal of Thanatology, II:1-2 (1972)

<sup>43</sup>Adah Maurer, "Maturation of Concepts of Death," Journal of Medical Psychology, XXXIX (1966), 35.

<sup>44</sup>Robert Kastenbaum, "The Kingdom Where Nobody Dies," Saturday Review, LV (December 23, 1972), 38.

<sup>45</sup>Maria H. Nagy, "The Child's View of Death," in Feifel, The Meaning of Death, pp. 79 ff.

<sup>46</sup>Chase Patterson Kimball, "Death and Dying: A Cronological Discussion," Journal of Thanatology, I:1 (January-February 1971), 44.

<sup>47</sup>Thesi Bergman, Children in the Hospital (New York: International Universities Press, 1965)

<sup>48</sup>James Robertson (ed.) Hospitals and Children (New York: International Universities Press, 1962)

<sup>49</sup>Gilbert Kliman, Psychological Emergencies of Childhood (New York: Grune and Stratton, 1968), p. 13.



child is terminally ill. Adamek<sup>50</sup> reports that the staff virtually avoid and isolate the terminally ill child. In reviewing Eissler's book, "The Psychiatrist and the Dying Patient"<sup>51</sup> I found no reference to a terminally ill child. Indeed, the relevant literature is quite sparse. Easson,<sup>52</sup> Sarah Sheets Cook<sup>53</sup> and Lindy Burton<sup>54</sup> cast light on physical and psychological needs of the terminally ill child. Their understanding of the child helped me to formulate my own ideas of the pastoral care of the terminally ill child.

Probably one of the greatest crises a family can experience is the anticipated loss of a child through a fatal illness.<sup>55;56</sup> The stresses imposed by the need to take care of the child over a period of months, tax the strongest family's adaptational resources. Binger

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<sup>50</sup>Mary Elaine Adamek, "Some Observations on Death and A Family," Nursing Science (August 1965), 264.

<sup>51</sup>Eissler, The Psychiatrist and the Dying Patient.

<sup>52</sup>William M. Easson, The Dying Child (Springfield, IL: Thomas, 1972)

<sup>53</sup>Sarah Sheets Cook (ed.) Children and Dying (New York: Health Sciences, 1974)

<sup>54</sup>Lindy Burton (ed.) Care of Child Facing Death (London: Routledge and Kegan Paul, 1974)

<sup>55</sup>Jerry M. Wiener, "Reaction of the Family to the Fatal Illness of a Child," in Bernard Schoenberg (ed.) Loss and Grief (New York: Columbia University Press, 1970), p. 87.

<sup>56</sup>J.A. Davis, "The Attitude of Parents to the Approaching Death of their Child," Developmental Medicine and Child Neurology, VI (June 1964), 286.

et al.<sup>57</sup> reports, "In half of the families at least one member reacted so strongly to the crisis as to need psychiatric help."

Marital problems and divorce, behavioral and school problems are also common.<sup>58</sup> The well siblings must deal with many conflicting feelings: anger towards parents; hostility, fear and guilt about a terminally ill sibling.<sup>59</sup> The family needs just as much help and support as the terminal child. There is some concern about the family in the literature<sup>60;61</sup> but in practice the family is still sadly neglected.

## 2.2 The Terminally Ill Adult and the Family

The age of the terminally ill patient will not only influence the Medical Team's approach, but will determine the reaction of the

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<sup>57</sup>C.M. Binger, et al. "Childhood Leukemia," New England Journal of Medicine, CCLXXX (February 1969)

<sup>58</sup>Yvonne Craig, "Marital Crises and the Dying Child," Marriage Guidance (December 1974), 215-217.

<sup>59</sup>J.M. Wiener, "Reaction of the Family to the Fatal Illness of a Child," in Schoenberg, Loss and Grief.

<sup>60</sup>Kübler-Ross, On Death and Dying.

<sup>61</sup>R.A. Kalish, "The Effects of Death Upon the Family," in Leonard Pearson (ed.) Death and Dying (Cleveland: Press of Case Western Reserve University, 1969)

patient to the illness.<sup>62;63;64</sup> The patient's reaction to hospitalization could be intense.<sup>65;66;67</sup> The loss or disfiguration of external organs may be experienced as very traumatic and the patient may respond accordingly.<sup>68;69</sup> The dying patients eventually come to know the diagnosis and the prognosis, notwithstanding efforts to conceal it from them.<sup>70;71</sup> The patient may experience

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<sup>62</sup>Walter C. Alvarez, "Care of the Dying," Journal of the American Medical Association, CL:2 (September 1952), 88.

<sup>63</sup>Elliott Jaques, "Death and the Mid-Life Crisis," International Journal of Psychoanalysis, XLVI (1965), 506.

<sup>64</sup>R.A. Kalish, "Some Variables in Death Attitudes," in Fulton, Death and Identity, pp. 170-181.

<sup>65</sup>Robert G. Wright and Thomas H. Holmes, "Psychological Aspects of Hospitalization," in Harold I. Lief, et al. The Psychological Basis of Medical Practice (New York: Harper & Row, 1963), pp. 219-220.

<sup>66</sup>Michael Balint, The Doctor, His Patient and the Illness (London: Pitman Medical, 1974), p. 216.

<sup>67</sup>"The Conspiracy of Silence in Cardiovascular Diseases," Geriatric Focus, V:1 (1966), 5.

<sup>68</sup>Bernard Schoenberg and Arthur Carr, "Loss of External Organs: Limb Amputation, Mastectomy and Disfiguration," in Schoenberg, Loss and Grief, p. 120.

<sup>69</sup>Edgar N. Jackson, "Body Image and Grief Response," in Austin H. Kutscher (ed.) Religion and Bereavement (New York: Health Sciences, 1972), p. 137.

<sup>70</sup>O.R. Bowen, "Should Patients Be Told When the Diagnosis is Cancer?," Journal of Indiana Medical Association, XLVI (April 1953), 303 ff.

<sup>71</sup>Cicely Saunders, Care of the Dying (London: Macmillan, 1959)

fear,<sup>72;73;74</sup> grief<sup>72;75</sup> and guilt.<sup>72;76</sup> Insightful and helpful are accounts of one nurse caring for one dying patient and relating her experience with that patient.<sup>77;78</sup> Other articles and publications deal with attitudes of patients and personnel about the topic of death.<sup>79;80</sup>

The patient is looking for someone, who demonstrates confidence in the hospital and yet is willing to take a place next to him/her as a fellow human being, willing to accompany him/her on his/her road during this time of crisis. The pastor is in an excellent position to fill this role. The pastor should not use this time for evangelism,<sup>81</sup> and should be willing to enter into an

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<sup>72</sup> Bernard Schoenberg and Robert A. Senescu, "The Patient's Reaction to Fatal Illness," in Schoenberg, Loss and Grief, p. 223.

<sup>73</sup> John Hinton, "The Psychology of Dying," in Norman Autton (ed.) From Fear to Faith (London: S.P.C.K., 1971), p. 43.

<sup>74</sup> E. Mansell Pattison, "Afraid to Die," Pastoral Psychology, XXIII:225 (1972), 41 ff.

<sup>75</sup> Robert Buxbaum, "Grief Begins not with Death, but Knowing it is Near," Texas Medicine, LXII:44-5 (1966), 44.

<sup>76</sup> Verwoerdt, Communication with the Fatally Ill, pp. 150-151.

<sup>77</sup> Roberta Eisman, "Why Did Joe Die?," American Journal of Nursing (1971) 71, pp. 501-503.

<sup>78</sup> E. Hoffman, "Don't Give up on Me," American Journal of Nursing, LXXI (1971), 60-62.

<sup>79</sup> Quint, The Nurse and the Dying Patient.

<sup>80</sup> D. Sudnow, Passing On (Englewood Cliffs: Prentice-Hall, 1965)

<sup>81</sup> J.W. Annis, "The Dying Patient," Psychosomatics, X:5 (1969), 290.

open and free relationship with the patient.<sup>82</sup> Non-verbal communication<sup>83</sup> is very important and the pastor should be sensitive about it, and know how to use it.<sup>84</sup> The pastor should help the patient in his/her anticipatory grief,<sup>85</sup> relating to the family and to the other members of the team.<sup>86</sup>

The family suffer with the terminally ill patient.<sup>87;88</sup> The integration of the family is threatened and the new patterns of relationships and roles must be established.<sup>89;90</sup> After the initial shock the family may be involved in anticipatory grief work. Their grief may be shared with the patient who stands to be cut off from all he has known and loved.<sup>91</sup> Anticipatory grief could also create

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<sup>82</sup>Bowers, Counseling the Dying, p. 67-68.

<sup>83</sup>James N. Lapsley, Salvation and Health (Philadelphia: Westminster Press, 1972), p. 147.

<sup>84</sup>Earl Grollman, Concerning Death (Boston: Beacon Press, 1974), pp. 34-5.

<sup>85</sup>Verwoerdt, Communication with the Fatally Ill, p. 83.

<sup>86</sup>L.L.Th. Brands, In De Schaduw van De Dood (Hilversum: Gooi en Sticht, 1974), pp. 132 ff.

<sup>87</sup>Verwoerdt, Communication with the Fatally Ill, p. 116.

<sup>88</sup>Field, Patients are People, pp. 207-208.

<sup>89</sup>David Maddison and Beverly Raphael, "The Family of the Dying Patient," in Bernard Schoenberg (ed.) Psychosocial Aspects of Terminal Care (New York: Columbia University Press, 1972), p. 193.

<sup>90</sup>Verwoerdt, Communication with the Fatally Ill, p. 116.

<sup>91</sup>Bowers, Counseling the Dying, p. 62.

problems for the family.<sup>92</sup> The family-members may experience anxiety,<sup>93</sup> anger,<sup>94;95</sup> guilt,<sup>96</sup> and employ defense mechanisms in order to cope.<sup>97</sup>

The family is totally neglected in the caring process.<sup>98</sup> The pastor has a special responsibility to reach out to them. The pastor could bring the family together and help them stay together by interpreting individual behaviors and by keeping the channels of communication open.<sup>99;100</sup> Family members must be helped to express their emotions and the pastor needs to be sensitive to feelings of

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<sup>92</sup>James A. Knight and Frederic Herter, "Anticipatory Grief," in Austin H. Kutscher (ed.) Death and Bereavement (Springfield, IL: Thomas, 1974), p. 198.

<sup>93</sup>Grollman, Concerning Death, pp. 62-63.

<sup>94</sup>Verwoerdt, Communication with the Fatally Ill, p. 128.

<sup>95</sup>Maddison and Raphael, "The Family of the Dying Patient," pp. 189-190.

<sup>96</sup>Verwoerdt, Communication with the Fatally Ill, p. 121.

<sup>97</sup>Maddison and Raphael, "The Family of the Dying Patient," pp. 191-192.

<sup>98</sup>Ann Cartwright et al. Life Before Death (London: Routledge and Kegan Paul, 1973), p. 193.

<sup>99</sup>Cancer Care, Inc. Catastrophic Illness in the Seventies (New York: 1970), p. 111.

<sup>100</sup>Virginia Barckley, "Grief, A Part of Living," Ohio's Health, XX (April-May 1968), 34-38.

grief,<sup>101</sup> anger<sup>102</sup> and guilt.<sup>103</sup> The pastor can be instrumental in helping to heal the wounds.

### 2.3 A Therapeutic Approach to Dying

We are confronted with the advance in modern medical science. As a result dying becomes a long extended process. How can the Church help people to live until they die? St. Christopher's Hospice in London, is an excellent example of a therapeutic community.<sup>104</sup> The patient and the family are the responsibility of the medical team, in the Hospice and at home.

The terminally ill patient and the family can only be adequately cared for by the medical team which includes members of every discipline.<sup>105;106</sup> The pastor cannot work effectively in a modern hospital without being a member of the team.<sup>107</sup> The pastor should know him/herself and his/her feelings about death and

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<sup>101</sup>Verwoerd, Communication with the Fatally Ill, pp. 129-130.

<sup>102</sup>Ibid., p. 128.

<sup>103</sup>Carl G. Carlozzi, Death and Contemporary Man (Grand Rapids: Eerdmans, 1968), p. 49.

<sup>104</sup>Information about St. Christopher's is obtainable from London.

<sup>105</sup>Easson, The Dying Child, p. 83.

<sup>106</sup>"Thanatology Looks at the Doctor and the Dying Patient," Medical World News (May 21, 1971), 34.

<sup>107</sup>Faber, Pastoral Care in the Modern Hospital.

dying.<sup>108</sup> She/he can use his time and energy well by implementing groups in the modern hospital.<sup>109;110</sup> The congregation must be involved in the caring too!<sup>111;112;113</sup> If we create a growth stimulating milieu, the dying patient and his/her family will grow and mature during this time of crisis. Each person has the innate potential to grow and to live until she/he dies. She/he will not only grow emotionally, but spiritually as well.<sup>114;115;116</sup>

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<sup>108</sup>David K. Switzer, The Minister as Crisis Counselor (New York: Abingdon Press, 1974), pp. 137-138.

<sup>109</sup>James E. Kilgore, Pastoral Care of the Hospitalized Child (New York: Exposition Press, 1968), p. 27.

<sup>110</sup>Irwin Hoffman and Edward Futterman, "Coping with Waiting," Comprehensive Psychiatry, XII:1 (1971), 79.

<sup>111</sup>W.J. Berger, "De Pastorale Begeleiding van de Terminale Patient," in F.J.A. Huygen et al. Menswaardig Sterven (Bilthoven, Amboboeken, 1974), p. 42.

<sup>112</sup>J.G. Straver, Zieken Thuis (Bilthoven: Amboboeken, 1972), p. 132 ff.

<sup>113</sup>Field, Patients are People, p. 61.

<sup>114</sup>Cicely Saunders, "Dimensions of Death," in M.A.H. Melinsky (ed.) Religion and Medicine (London: S.C.M. Press, 1970), I, 114.

<sup>115</sup>Ruth Abrams, "The Patient with Cancer—His Changing Pattern of Communication," New England Journal of Medicine, CCLXXIV (February 10, 1966), 321.

<sup>116</sup>Brands, In De Schaduw van De Dood, p. 127.



## CHAPTER 3

### CULTURAL ATTITUDES TOWARDS DYING

The attitude towards death changes from time to time and from culture to culture. Elizabeth Kübler-Ross<sup>1</sup> describes the way she experienced death in her childhood:

I remember as a child the death of a farmer. He fell from a tree and was not expected to live. He asked simply to die at home, a wish that was granted without questioning. He called his daughters into the bedroom and spoke with each one of them alone for a few moments. He arranged his affairs quietly, though he was in great pain, and distributed his belongings and his land, none of which was to be split until his wife should follow him in death. He also asked each of his children to share in the work, duties, and tasks that he had carried on until the time of the accident. He asked his friends to visit him once more, to bid good-bye to them. Although I was a small child at the time, he did not exclude me or my siblings. We were allowed to share in the preparations of the family just as we were permitted to grieve with them until he died. When he did die, he was left a home, in his own beloved home which he had built, and among his friends and neighbors who went to take a last look at him where he lay in the midst of flowers in the place he had lived in and loved so much. In that country today there is still no make-believe slumber room, no embalming, no false make-up to pretend sleep. Only the signs of very disfiguring illnesses are covered up with bandages and only infectious cases are removed from the home prior to the burial.

How totally different is this from present day practices in our modern society. When I was nine years old, my sister who was eleven became ill. We were good friends and emotionally very close to each other. After three days in bed at home her condition deteriorated and she was rushed to the hospital. I remember my anguish,

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<sup>1</sup>Elizabeth Kübler-Ross, On Death and Dying (New York: Macmillan, 1969), p. 5-6.

desperation and fear when she was taken away. I did not see her again. She died the same night. I was not allowed to view her body and to say my good-bye although I asked my father.

Verwoerd<sup>2</sup> claims that our attitudes toward death are largely derived from our experience with the death of others. We assume what it must be like from what we see. What do we see? The person is taken to a hospital or nursing home, isolated in a little room as if under quarantine; everything cold, indifferent, impersonal. We may think of death as a sleep from which one can never be awakened, or as a journey from which one never returns. When we relate this to ourselves, death may represent eternal sleep, unconsciousness, aloneness, loss of loved ones, separation from pleasures or earthly life, loss of self-control and personal identity and loss of intactness of the physical self, and eternal isolation and rejection. Rather than thinking about death in this way we repress our thoughts and deny the reality of death. Berger quotes Borkenau who claims that we find ourselves in a death denial cultural period.<sup>3</sup>

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<sup>2</sup>Adriaan Verwoerd, Communication With the Fatally Ill (Springfield, IL: Thomas, 1966), p. 5.

<sup>3</sup>Willem J. Berger, Leren Bijstaan Van Stervenden (Nijmegen: Dekker and Van De Vegt, 1968), p. 4-5.

### 3.1 The Tabu on Death and Dying

#### 3.1.1 The Concept "Tabu"

The word "tabu" was taken from the Polynesian in the 18th century, meaning "prohibition" or "forbidden." It was tied to religion and magic in primitive cultures. In a certain sense the concept "Holy" or "Sacred" is related to "tabu." What is holy or sacred is secluded for God and for worship. It relates to objects which could not be touched, viewed or tread upon. At times it was reserved for priests or religious leaders who stood in an unique relation to God.<sup>4</sup> Webster<sup>5</sup> explains the meaning of "tabu" to be:

- (a) forbidden to profane use or contact because of supposedly dangerous supernatural powers.
- (b) a prohibition against touching, saying or doing something for fear of immediate harm by a superhuman force.
- (c) a prohibition imposed by social custom or as a protective measure
- (d) banned on grounds of morality or taste.
- (e) banned as constituting a risk.

We do not use the word "tabu" as a prohibition on purely rational grounds. Included in the meaning is keeping a distance and the hesitation to allowing ourselves into the situation. A tabu rests on objects, situations and actions in which a person is emotionally affected because of the fact that his/her total existence is questioned or threatened. It concerns an object, situation or action,

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<sup>4</sup>L.L.Th. Brands, In De Schaduw Van De Dood (Hilversum: Gooi En Sticht, 1974), p. 54.

<sup>5</sup>Webster's New Collegiate Dictionary (Springfield, MA: G. and C. Merriam, 1974)

approached by a specific culture in a reserved way. Because of the fact that people are unacquainted with it they feel threatened in tabu-situations. The person reacts to the threatening situation by means of anxiety, hesitation, denial, avoidance, apathy and clumsiness.

In the Victorian era an enormous sexual tabu developed and in today's culture we find it still difficult to move away from the tabu and grow in authentic sexual relations.<sup>6</sup>

### 3.1.2 The Concept "Tabu" in Our Culture

The twentieth century man, refusing to sacrifice his/her pride in order to maintain peace has loosed upon him/herself, his/her progeny, and his/her nation a holocaust of death. We have experienced death by violence of all sorts and on a scale heretofore unknown, but people in this century have not been able to discuss or to consider deeply the meaning of death.<sup>7</sup> Beatty<sup>8</sup> claims that there is evidence supporting the idea that many people do not even want to think about death. It is true that we adapt and adjust to our times because we are part of them and close to them. Part of our adaptation has been to protect ourselves against the honest facing of violence and death. One of the psychological defenses we have

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<sup>6</sup>Brands, In De Schaduw Van De Dood, pp. 59-60.

<sup>7</sup>Milton McC. Gatch, Death (New York: Seabury Press, 1969), pp. 2-3.

<sup>8</sup>Donald Beatty, "Shall We Talk About Death?" Pastoral Psychology, VI (February 1955), 2-3.

developed, according to Jackson,<sup>9</sup> is to block off what is too painful to confront. So we stop thinking and talking and feeling about this important area of human experience.

Robert Fulton, a sociologist interested in death and dying and now director of the Center for Death Education and Research at the University of Minnesota in Minneapolis writes:<sup>10</sup>

Death is now a temporal matter. Like cancer or syphilis, it is a private disaster that we discuss only reluctantly with our physician . . . . Those who are caught in the throes of death are isolated from their fellow human beings, while those who have succumbed to it are hidden quickly from view . . . . Death, like a noxious disease, has become a taboo subject, and as such it is both the object of much disguise and denial as well as of raucous and macabre humor.

Grollman<sup>11</sup> says that the new four-letter word of pornography is DEAD. Much of America seems involved in a vast conspiracy to hush up this "obscene" utterance. Like a noxious disease, death has become a forbidden subject, replacing sex as an object for repression. Many not only avoid the word dead, they just pretend that loss of life does not occur. Grollman quotes the anthropologist, Geoffrey Gorer who stated that 44% of parents do not even tell their children when someone dies in the immediate family! The same adults talk openly with their offspring about the biological processes surrounding the

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<sup>9</sup>Edgar N. Jackson, When Someone Dies (Philadelphia: Fortress Press, 1972), p. 20.

<sup>10</sup>Robert L. Fulton (ed.) Death and Identity (New York: Wiley, 1965), p. 4.

<sup>11</sup>Earl Grollman, Suicide (Boston: Beacon Press, 1971), p. 121.

beginning of existence. However, they strangely avoid the evidences of the end of the life cycle.

We know that death comes to all of us. The younger we are, the more likely we are to think that it comes to others, not to us. But, deep down, we all know that sometime or other, death comes. This knowledge, however, seems to be in the category of those things that we "know about" rather than those we "know." It is accepted by our intelligence, but has not worked its way into our feeling knowledge. We know it in theory, but we have little actual feeling that it applies to us,<sup>12</sup> or we fear (a feeling) that it does apply to us and so deny it.

### 3.1.3 Reasons for the Tabu

Richard Doss<sup>13</sup> finds three reasons for the denial of death in our culture. The first is psychological. Sigmund Freud believed that every person in the unconscious mind is convinced of his own immortality. Freud discovered that denial functions as a coping mechanism enabling patients to handle their anxiety about death. Every time we attempt to contemplate our own death, we do so as spectators, that is, we are unable to think or imagine our own non-being. Elizabeth Kübler-Ross contends that denial enables us to live in the midst of massive violence and yet, at the same time privately

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<sup>12</sup>Beatty, "Shall We Talk About Death?" p. 12.

<sup>13</sup>Richard W. Doss, The Last Enemy (New York: Harper & Row, 1974), pp. 4-8.

maintain that it will occur "to thee and to thee but not to me."<sup>14</sup>

The second reason why our society is death-denying is cultural. Our culture emphasizes youthfulness, vitality and productivity and death is pushed out of life. Death asks less attention because it is less present and less threatening.

A third reason that helps to explain our death-denying culture is religious and theological. From the Puritan settlement of New England to nineteenth-century life on the western frontier, a theological framework supported and interpreted man's place in society and his relationship with nature and God. Men believed and felt that God had a purpose for life, and more, that every man could be dealt with openly and treated as a natural part of life. The twentieth century has seen a virtual abolition of the traditional Christian framework in many places and with many people, with no new proposal to take its place. Secularization has separated modern people from older understandings of humankind and society, and in so doing has separated death from the means by which it had been explained for so many years.

Other reasons may be the decline in the number of extended families where three generations of relatives would live together. Today, newlyweds more often follow the residential pattern of neolocality, establishing their own household away from both sets of

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<sup>14</sup>Kübler-Ross, On Death and Dying, p. 12.

parents. The death of older family members, once experienced by the whole living group, is thus segregated both physically and emotionally from the younger members. Accomplishments in the fields of public health and medicine have made the death of infants and children much less expected or accepted. Moreover, children today tend to be shielded from funeral ceremonies and thus have little direct experience with death prior to adulthood.

Corresponding increase in the number of small nuclear families as living units has further complicated this picture of unpreparedness. The death of a family member within a dyadic or triadic living group is far more traumatic and devastating to role relationships than would be the case in larger families.

Sex is considered to be a proper area of discussion within the family unit, death and dying is rarely brought up. Deaths have been eliminated from fairy stories and nursery rhymes and both children and adults are shielded from it.<sup>15</sup> As a result death has been isolated and denuded. With no meaningful framework for understanding death, our culture has adopted a style of denial and avoidance.

Theologian Paul Tillich argues that most people deal with death and dying by looking at the "immediate future," anticipating it, working for it, hoping for it, and being anxious about it while cutting off from our consciousness the end, the last moment of our

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<sup>15</sup>Ellen Scheiner Zinner, "A proposal: Developing the role of the clinical associate in the field of terminal patient care," Journal of Thanatology, 1:3 (1971), 156 ff.



future.<sup>16</sup> Robert Fulton<sup>17</sup> tries to answer the same question: "How do we cope with death?" when he says that as never before we choose to disguise death and pretend the meanwhile that it is not the basic condition of all life. Except among the aged, death is not considered an open or polite topic of conversation; some newspapers segregate it by devoting special pages to it while seeing to it that no mention of death appears in the society column; the dead are hidden from view as quickly as possible and removed to a funeral home; children are protected from direct contact with, and observation of, death and the dead. An extensive poll conducted by Kavanaugh<sup>18</sup> among college students revealed that 78% had yet to see a dead person up close. More than 92% had yet to witness a death.

When a person is dying, the whole community enters into a secret alliance to keep the painful, but nevertheless real fact from him/her. Weisman found that one of the first questions asked by solicitous family and friends is whether to tell. As a rule the decision is not to tell. "Personally I would want to know, Doctor. But after all he's been through, he might get too upset and I just couldn't face it."<sup>19</sup> It does not matter whether the patient wants the

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<sup>16</sup>Paul Tillich, "The Eternal Now," in Herman Feifel (ed.) The Meaning of Death (New York: McGraw-Hill, 1965), pp. 31-32.

<sup>17</sup>Fulton, Death and Identity, pp. 100-101.

<sup>18</sup>Robert E. Kavanaugh, Facing Death (Baltimore: Penguin Books, 1974), p. 15.

<sup>19</sup>Avery D. Weissman, On Dying and Denying (New York: Behavioral, 1972), p. 17.

truth; she/he is not given it, with the result that she/he is isolated, and there is no honest communication. Leo Tolstoy described this situation most poignantly in his novella "The Death of Ivan Ilych": In the bosom of his family, surrounded by friends, he was more alone than if he had been at the bottom of the sea, or the other side of the moon.<sup>20</sup> The majority of Americans can expect to die in a hospital or in a home for the aged.<sup>21</sup> If finally death appears really inevitable for the patient in a modern hospital, then she/he is immediately moved to a separate room, so that in the whole of the hospital there is no overt sign of the reality of death. One might well argue that the whole atmosphere of the hospital is geared to concealing the reality of death from the patient and his/her family.<sup>22</sup>

The universal fear of death extends to the hospital personnel: physicians, nurses, orderlies and the rest of the team. Says Elizabeth Kübler-Ross: "We often fail to see the dying patient as an ordinary human being, one who has great emotional needs as well as physical ones." She tells how she timidly approached a terminally ill patient:

He was so angry that he displaced it onto everyone. The nurses hated to go near him. But he wanted to talk, and as soon as he

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<sup>20</sup> Leo Tolstoy, The Death of Ivan Ilych (New York: Signet, 1960), p. 149.

<sup>21</sup> Kavanaugh, Facing Death, p. 5.

<sup>22</sup> Heije Faber, Pastoral Care in the Modern Hospital (Philadelphia: Westminster Press, 1971), p. 62.

began to express himself, I found out why he was angry. He had so much to say and no one had been willing to really sit down and listen.<sup>23</sup>

The fact is that death is a difficult subject to talk about. There is no language system to describe it because language belongs to the living and death can only be observed by the living. Medicine can do nothing to dispel this mystery because it is a science which works with empirical methods, observing, exploring and describing the phenomenon of biological life. Even physicians tend to shy away from the subject of dying and death because their profession has placed them firmly on the side of biological health. The physician sides with health against illness and with life against death.<sup>24</sup>

Most individuals avoid the subject of death in any way that might touch them personally. They find it too anxiety provoking. Consequently, they tend to live as though death were no possibility for them.

The church consisting of human beings with their fears and anxieties and finding itself within a specific culture and society with its own values, beliefs and tabu's does not manage to stay free of the denial of death, the tabu on death.

In the Roman Catholic Church the Sacrament of the last rites which was usually only given to a dying patient was changed by the Second Vatican Council in the early 1960s to the Sacrament of the

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<sup>23</sup>Grollman, Suicide, pp. 122-123.

<sup>24</sup>Verwoerd, Communication with the Fatally Ill, p. 4. . .

Anointing of the sick. This broader definition of the Sacrament allowed it to be given to a person who is seriously ill, although he may not be in a critical condition.<sup>25</sup>

In the new hymnal of the Dutch Protestant Alliance all hymns dealing with death and everlasting life were removed.<sup>26</sup>

It is almost impossible to speak about death and dying spontaneously anywhere in our society. When faced with a dying person or with someone who is bereaved, we become acutely embarrassed, "mortified," and cannot talk about death without guilt and anxiety. Our reluctance to speak about death is only partially explained by our sensitivity, sympathy and compassion.<sup>27</sup>

### 3.2 The Change in Attitude

In 1971 Earl A. Grollman wrote:<sup>28</sup>

No longer can the topic of death be avoided or evaded. Mental health is not the denial of pain but the frank acknowledgment of it. The world of biology is the world of the living and dying. There can be no death without life and, conversely, no life without death. Emotion is natural, inevitable, and highly desirable. Grief is more than sorrow. It is a necessary process that forces a person to adjust to changed circumstances. Even though no mortal has pierced the mystery surrounding death, maturity should force man to recognize that dying and death are phases of life and living.

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<sup>25</sup>American Hospital Association, Manual on Hospital Chaplaincy (Chicago: 1970), p. 52.

<sup>26</sup>P.J.C. Janssen, "Het Bijstaan Van Stervenden" (unpublished Ph.D. Dissertation, R.C. University, Nijmegen, 1970), p. 1.

<sup>27</sup>Weisman, On Dying and Denying, p. 16.

<sup>28</sup>Grollman, Suicide, p. 123.

We live in a changing society. What is rejected today is accepted tomorrow and vice versa. The tabu on death and dying is being attacked on many levels of our society. There has been a rise in interest in the subject of death. Since Elizabeth Kübler-Ross published "On Death and Dying"<sup>29</sup> in 1969 there has been a tremendous increase in literature on death and dying. Reading about death and dying stimulates thinking and talking about it. Major magazines feature it. A national monthly recently reported half again as many respondents to a poll on death as to a poll on sex.<sup>30</sup> The global impact of such events as the assassination of one President and two important national figures, the war in Southeast Asia, the phenomenon of organ transplantation, and a steady state of anxiety about nuclear holocaust, chemical and biological warfare, and environmental destruction seem to have triggered a wave of fascination, if not confrontation, with death and dying.

Television has become a powerful influence in changing our attitudes on death and dying, particularly death associated with war. War was always regarded as something over there; on the other side of the Atlantic ocean or on the other side of the Pacific ocean. The headlines in our papers about how many people were killed or shot down were impersonal and did not touch us. But television newscasts brought the Vietnam and Cambodia war into our living room. We saw

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<sup>29</sup>Kübler-Ross, On Death and Dying.

<sup>30</sup>Kavanaugh, Facing Death, p. 3.

casualties, we saw refugees. That was for real. It heightened people's consciousness of the reality of death and destruction through war.

It is difficult to determine whether artistic media reflects the cultural changes or whether they are pace setters to some degree. It may be both. There is much more realism in films around death than before. Examples are *Godfather*, *Easy Rider* and *Bonnie and Clyde*.

The present day youth who are growing up with the Bomb, in a society that builds bomb shelters and talk about the destruction of a nuclear war, is not able to deny death to the extent previous generations had denied it. This is reflected in many modern folk songs.<sup>31</sup>

When New York University offered an undergraduate course titled "The Meaning of Death," students flocked to sign up. Kavanaugh reports: "Thirty-five students were forecast for my recent course on thanatology. More than 200 attended the first lecture."<sup>32</sup> Seminars and workshops on death and dying are being given in many places across the country and many people show their interest. The rise of organizations and study groups on euthanasia is further evidence of the melting of the death tabu.

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<sup>31</sup>The Beatles, "Eleanor Rigby"; Bernie Taupin and Elton John, "Candle in the Wind"; Bob Dylan, "Blowin' in the Wind"; Country Joe MacDonald and the Fish, "Fixin' to die Rag."

<sup>32</sup>Kavanaugh, Facing Death, p. 3.

In a survey of medical schools made for the Foundation of Thanatology, Schoenberg and Carr found that two-thirds of the students want curriculum changes, asking for discussions and lectures about the controversial issues connected with the care of dying patients—euthanasia, definitions of death, ethics of organ transplantation, and the possible risk of narcotics addiction in terminal cases. They would also like more contact on an interdisciplinary level with the other members of the team; the chaplain, social worker, nurse.<sup>33</sup>

Riley<sup>34</sup> points out that there is a growing concern with the individual's "right" to die with dignity in both medical and theological circles and increasing attention is being paid to death in the arts and in the mass media. Research indicates that death is seen as a threat to the activity of life and it is not denied. The meaning of death in contemporary America may be changing and the indication is that the tabu on death is being relaxed.

It may take a long, long time but eventually people will become more comfortable with the topic of death in the same way they became more able to talk about sex without blanching, without using euphemisms, or without being unnecessarily crude, if the trend continues in this way.

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<sup>33</sup>"Thanatology Looks at the Doctor and the Dying Patient," Medical World News (May 21, 1971)

<sup>34</sup>John W. Riley, Jr., "What People Think About Death," in Orville G. Brim et al., The Dying Patient (New York: Russel Sage Foundation, 1970), p. 40.

### 3.3 How is the Pastoral Care of the Terminally Ill Patient Influenced By the Tabu?

Life—and death—are different today. Death is likely to come to a person after seven or more long decades, and sometimes even in a terminal illness, life is prolonged through the use of drugs and sophisticated medical equipment. Though there is a new surge of interest in the subject, death and dying have been forbidden topics for decades. And the tabu has inflicted terrible damage on dying persons, on their families and friends, and even on the health professionals who care for the dying.<sup>35</sup> The pastor is certainly not excluded from this group. Because of the tabu, too many patients have suffered the kind of end that isolated them from those who cared.

Because of the tabu on death we have basic concepts and assumptions about it. Death is kept at a distance. It is accepted as happening to others and not to yourself. Even the churches who had the "monopoly" in death and dying for many years became helpless. Ministers are struggling with analogies and metaphors from the Old Testament or the New Testament. They are uncomfortable in the presence of death and struggle to take the attention of the dying patient away from him/herself and of his/her experiencing his/her dying. They offer images of "a new life" and forbid the patient to withdraw into himself and share his feelings. Their own anxiety about death makes it impossible to deal with the feelings and

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<sup>35</sup>Nancy Doyle, "The Dying Person and the Family," Public Affairs Pamphlet, No. 485 (1972), 2.



anxieties of others in an empathetic and honest way.<sup>36</sup> Until the pastor can accept the personal reality of death as a common legacy of humankind, pertaining to every person, he/she will remain caught in a dense web of artifice and denial. Natural awareness of our mortality will make the pastor less disingenuous, less guilty, and less fearful in the presence of someone else's truth. The principle worth in sharing truth is to encourage viable responsiveness between people as long as possible.<sup>37</sup>

After the pastor has come to terms with talking about death, she/he can devote more of his/her energy to the patient, caring for him/her in an authentic, empathetic and honest way, sensitive to the physical, psychological, social and spiritual needs. Real connectedness and affirmation, real consolation, hope and support is only possible in an honest atmosphere of the acceptance of the reality of death.

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<sup>36</sup>Georg Sieber, Ouder Worden (Nijkerk: Uitgeverij G.F. Callenbach, 1972), p. 106.

<sup>37</sup>Weisman, On Dying and Denying, p. 18.

## CHAPTER 4

### ALTERNATIVE PLACES OF DYING IN MODERN SOCIETY

Progress in medical science and the enhancement of life generally in the past half-century have meant, among other things, that the proportion of elderly persons in the United States of America has greatly increased. Twenty million people, or 10% of our present population, are over 65 years of age. This population is rapidly increasing. It is estimated that by the end of the decade, this age group will number 24 million persons.

Death is primarily the experience of the aged. Of those who will die in the United States annually, almost two-thirds will be 65 years of age or older. Children under the age of 15, on the other hand, will account for less than 6% of the total deaths. This is in sharp contrast to the mortality statistics of 1900. In that year, children under the age of 15 accounted for 53% of the total deaths even though they constituted approximately one-third of the population, as they do now. In that same year, persons aged 65 and over accounted for 4% of the total population but 17% of all death. The changes in mortality statistics reflect a general increase in life expectancy. A person born in 1900 had a life expectancy of 47.3 years, whereas a person born in 1967 could expect to live 70.5 years.

The context in which dying and death are experienced in our society has also undergone a significant change in recent years. Of the two million deaths estimated for 1972, almost two-thirds of them

(±65%) will take place outside the home in either a hospital or a nursing home. The trend is toward increased hospitalization and institutionalization of the chronically ill and dying patient. The data for 1960 show that 60% of all deaths occurred in hospitals or institutions. Furthermore, the number of persons who will go to an institution to die can be expected to increase owing to medicare, more sophisticated medical technology, and the progressive segregation of the aged from their families. The extension of medical health services, therefore, has not only changed the age at which a person can expect to die, but has also changed the place of his death.<sup>1</sup>

In England Cartwright et al.<sup>2</sup> (whose research included adult deaths from all causes) found that the main difference between those dying at home and those dying in a hospital lay in their household composition and whether or not they had children, particularly daughters, rather than the number, severity or length of time for which they had symptoms. In her study of patients dying of a malignant disease, Ward<sup>3</sup> found no significant differences in household composition whether the patient died at home or in a hospital, with the exception of the cases where the patient had been living alone. Even where the household included young children half the

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<sup>1</sup>Robert Fulton, "Death and Dying: Some Sociologic Aspects of Terminal Care," Modern Medicine, XL (May 29, 1972), 75.

<sup>2</sup>Ann Cartwright et al., Life Before Death (Boston: Routledge and Kegan Paul, 1973), pp. 67-68.

<sup>3</sup>Audrey W.M. Ward, "Terminal Care in Malignant Disease," Social Science and Medicine, VIII:7 (1974), 419.

patients died at home and half in hospital. There is some evidence that patients generally prefer to die at home, but the contrary view is also expressed that some patients would wish to spare their families if at all possible, from the trouble and distress involved and prefer to be taken to a hospital.<sup>4</sup>

#### 4.1 Dying in the Modern Hospital

An elderly patient, just arrived in the general ward of a modern hospital, is crying softly. While her sister helps her to bed, a harassed nurse rushes in, places a specimen bottle and several chart sheets on the bedside stand and immediately begins to write. "Do you have any jewelry with you?" asks the nurse. The patient moans and swallows hard, while the nurse sighs and wiggles her pen. "No" says the patient. "Oh, my God, help me." She covers her face with her hand, and moans. "Do you have any false teeth?" Still moaning, the patient shakes her head, then suddenly tries to grab a small bottle from her sister. "Give me my pills, please, don't take them away." The sister jumps back, saying, "You know you can't keep them." "Yes, but when I have the pain, I have to wait too long. I know this place, I've been here eight times." The old woman is sobbing. "Now, you know you can't keep them here," interjects the nurse. "I told you so," the sister adds. "But I can't stand the pain. Oh, why doesn't God help me?" "Can you give me a urine sample?" asks the nurse.<sup>5</sup>

Outside the hospital the nurse would probably have been sympathetic with the old woman's distress. Within the hospital, however, she responds to the "order" given her by her superiors, instead of to the patient. The nurse, therefore ignores, i.e., doesn't

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<sup>4</sup>Ibid., p. 418.

<sup>5</sup>Anna Baziak, "The Language of the Hospital and Its Effect on the Patient," in James K. Skipper (ed.) Social Interaction and Patient Care (Philadelphia: Lippincott, 1965), p. 272.

"perceive" any responses of the patient which cannot be used on the admission form.

The modern hospital is a highly complicated, highly specialized machinery, primarily oriented toward saving lives and toward patients with an expected future. Here we have a close-meshed network of spaces, apparatus, specialized tasks, hierarchical relationships, horizontal and vertical lines of communication, shared responsibilities, unassailable expertise, prized status relationships and prestige structures full of latent conflict. Here we have a restless atmosphere in which sharply timed procedures and techniques demanding scrupulous care, place all those taking part at times in an almost tangible nervous tension with one another.<sup>6</sup>

The modern hospital is often a difficult place for the dying patient and the family. The professional staff faces heavy demands to deal with treatable patients. Untreatable patients and patients with poor life expectancy are frequently given low priority. Death is looked upon as a failure and the dying patient is, in a sense, an embarrassment. A dying patient will sometimes apologize for being such a trouble, feeling guilty perhaps, for taking time from those with a good chance of recovery who absorb much of the staff's attention. In the teaching hospital the dying patient, at the end of his/her extended illness, is considered neither a good teaching case nor an interesting treatable case, and some disposition, other than

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<sup>6</sup>Heije Faber, Pastoral Care in the Modern Hospital (Philadelphia: Westminster Press, 1971), p. 8.

remaining in the hospital is sought at the very time that some stabilizing influences may be important. The modern hospital tends to be highly impersonal.<sup>7</sup>

In many cases the patient is taken away from his own familiar surroundings, during the final and most intimate moments of his/her life. From intimate, personal, loving surroundings she/he is taken into an impersonal, neutral, technical-scientific atmosphere of the hospital. The patient comes unbidden to a large organization which awes and irritates him/her, even as it also nurtures and cures (other people). As she/he strips his clothing, so she/he strips off, too, his/her favored costume of social roles, his/her favored style, his/her customary identity in the world. She/he becomes subject to a time schedule and a pattern of activity not of his/her own making.<sup>8</sup>

The patient is now in the situation of becoming an object, the object of examination, of treatment, of nursing. She/he lives in a network of related functions in which a large number of people deal with him/her: the specialist, the radiologist, the hospital analyst, the nursing staff, etc. Yet she/he him/herself has virtually little or nothing to do in all this; she/he has to let him/herself be treated and is entirely dependent on decisions made about him/her by others. She/he suddenly has to entrust him/herself to a number of

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<sup>7</sup>Melvin J. Krant and Alan Sheldon, "The Dying Patient—Medicine's Responsibility," Journal of Thanatology, 1:1 (January-February 1971), 5.

<sup>8</sup>Robert N. Wilson, "The Social Structure of a General Hospital," in Skipper, Social Interaction and Patient Care, p. 236.

people he does not know in an unfamiliar situation.<sup>9</sup> In this situation she/he has to prepare for his death, say goodbye, finish unfinished business and finally die. More than anything else she/he needs to be reassured and find security.

The cancer patient, in particular, is apt to encounter a series of dislocations. The patient is frequently referred from one expert to another (surgery, radiotherapy, chemotherapy) and even from one institution to another. There may well be no one physician who has been in charge of the patient throughout his extended illness. Whatever information has been openly discussed with the patient and his/her family concerning his diagnosis and prognosis is seldom available to the next physician. The patient's understanding of and feelings about his/her disease and his/her future are frequently left unclear as he changes doctors. Therefore, the patient is apt to approach his death with uncertainty as to who his/her physician really is, and with no one to guide him/her toward an ultimate care program and goal, let alone help him/her to discover how to endure his/her experience.<sup>10</sup>

Hinton<sup>11</sup> feels that the more gentle care necessary for treating dying people may not be at its best in hospitals catering for acute cases. The traditional design of large wards with a few

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<sup>9</sup>Faber, Pastoral Care in the Modern Hospital, p. 19.

<sup>10</sup>Ibid., p. 6.

<sup>11</sup>John Hinton, Dying (Baltimore: Penguin Books, 1974), p. 158.

single or double rooms does not allow much flexibility in the choice of a suitable bed for the dying, or sudden transfer of a person with deteriorating health from a full ward to a lonely side-ward can have bleak implications. For convenience, therefore, the dying patient may be moved to a corner or if fortunate enough, to a side ward, and is thereby isolated even more. The breathless speed of a busy ward is ill-suited to the dying patient's need for tranquility and peace.

Without exception studies indicate that communication between dying patients and both staff and relatives is poor. To some extent, this can be explained by the fact that interaction with persons who have no future is frustrating in our culture. Such individuals suffer a sharp loss in social value.<sup>12</sup>

In many cases there is conflict between the hospital and the family, with the hospital attempting to encourage the dying patient to spend more of his/her days at home, while the family, feeling itself helpless to handle the emergency needs of the patient, insists on the staff maintaining the patient in the hospital.<sup>13</sup>

Families generally express the wish in the common preference for retaining more social-psychological control over the patient's last hours, leaving to the staff the management of medical and nursing

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<sup>12</sup>Diana Crane, "Dying and Its Dilemmas as a Field of Research," in Orville G. Brim et al., The Dying Patient (New York: Russel Sage Foundation, 1970), p. 313.

<sup>13</sup>Sol Levine and Norman A. Scotch, "Dying As an Emerging Social Problem," in Brim, The Dying Patient, pp. 219-220.



care. Family members want as much chance as possible to be with the dying person, and want staff members to be more considerate of the social psychological dimensions of staff relationships with the patient during his/her last hours. The family wants to be present during the last hours, be continually informed, hold the patient's hand and talk with him/her. In many hospital situations, however, family members are put in a waiting room and are forbidden to be with their loved one at the end. They are told that their presence is too stressful for the patient who "must rest" as he dies! Thus the probability is low that the family will be with the patient at death, even if they are waiting just down the hall from him/her! Consequently they will experience his/her death as an announcement, not as a graceful passing.<sup>14</sup>

The depersonalizing effect of institutional care gives today's average citizen—including today's physician—the sobering prospect of meeting his/her demise either in grim isolation or in the midst of bustling activity, bristling with tubes and listening to the steady beat of pumps, respirators and monitoring devices—but with nobody near who has any time to talk or to answer questions.<sup>15</sup> Much mental suffering is caused by the "depersonalization" that occurs in most, if not all, big hospitals. Despite the fact that the patient is dying

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<sup>14</sup>Barney G. Glaser and Anselm L. Strauss, Time For Dying (Chicago: Aldine, 1974), p. 191.

<sup>15</sup>"Thanatology Looks at the Doctor and the Dying Patient," Medical World News (May 21, 1971), 30.

and although it is the patient's illness, he/she is not consulted about anything, his/her cooperation is not sought. Resentment at everything and with everybody begins to build up, symptoms tend to multiply and worsen—all because the patient is not being treated as a person!

Robert Fulton<sup>16</sup> says that dying in an institution is a profoundly different experience from what it can be in one's own home. The restraints placed upon a patient as well as upon his family and friends often serve to aggravate his/her isolation not only from them but also from the hospital staff. Procedural rituals of deception, disguise, and denial with regard to dying and death are commonplace.

#### 4.2 Dying at Home

Most people express a preference to die at home.<sup>17</sup> This general impression has been confirmed by means of systematic studies both of the opinions of patients of cancer in the hospital and the relatives' reports of the views of those who were cared for at home. According to Hinton<sup>18</sup> one person in three dies at home and the remainder in other institutions and a variety of places. If a dying person can have adequate care in his/her own home there is much to be said in favor of ending his/her days there. Facing the finish of

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<sup>16</sup>Fulton, "Death and Dying . . . ," p. 75.

<sup>17</sup>Hinton, Dying, p. 150.

<sup>18</sup>Ibid., p. 149.

mortal life, often apprehensive or sad, it seems unkind to remove him from the familiar comforts of home. Saunders<sup>19</sup> has described the importance of people who are dying not feeling alone at the time of death and of "good-byes" from the point of view of both patients and their families. Cartwright et al.<sup>20</sup> found in their study that 87% of those who died at home had relatives or friends with them at the time, and for those in hospitals or institutions the proportion was 24%. The overall proportion was 53%.

The closer the kinship relatedness, attachment, and proximity, the more likely the burden of care at home will be assumed by the family.<sup>21</sup> Dying persons gain so much by being cared for by an affectionate family; they are better able to maintain themselves as individuals. Remaining at home, not swallowed up in the possible anonymity of the dying hospital patient, they need not doubt they are still part of the family.<sup>22</sup>

The data from a Chicago report on many aspects of the care of cancer patients shows that the progress of patients at home did not differ so much from those in the hospital. The length of the period of terminal care was similar for patients at home and in the hospital.

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<sup>19</sup>Cicely Saunders, "The Moment of Truth: Care of the Dying Persons," in Francis G. Scott (ed.) Confrontations of Death (Corvallis: Oregon State University, 1971), pp. 111-122.

<sup>20</sup>Cartwright, Life Before Death, p. 187.

<sup>21</sup>Kathy Calkins, "Shouldering a Burden," Omega, III:1 (1972)

<sup>22</sup>Hinton, Dying, p. 155.

The majority will have a terminal period requiring special care lasting a few days or weeks and not usually exceeding three months.<sup>23</sup>

A survey done in England found that 2/3 of the terminal patients cared for at home experienced moderate to severe mental and physical suffering.<sup>24</sup> In the absence of immediately available skilled professional care at home, physical discomfort may not be dealt with at once and distress can soon develop.

Many patients going home after a prolonged period of hospitalization find it very difficult to adjust at home; to accept the fact that during his absence his/her responsibilities have been taken over by someone else. Few people are sufficiently flexible, sufficiently secure, to be able to adjust to prolonged dependency in their own home without help. If the family is sensitive and understanding this could be worked out in a mutually satisfying way.<sup>25</sup>

In the environment of his/her own home the patient can continue with his normal living habits to the extent of his/her functioning ability. There are distractions and satisfactions within a household, contacts with the family, relatives and neighbors and a feeling of continuing in the mainstream of life. There is opportunity to pull together unfinished business, plans for the future care of the children and other relatives, a gradual transfer of roles and

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<sup>23</sup>Ibid., pp. 68-69.

<sup>24</sup>Ibid., p. 73.

<sup>25</sup>Minna Field, Patients Are People (New York: Columbia University Press, 1967), pp. 124-130.

responsibility within the family and completion of any necessary legal and business matters.<sup>26</sup>

With the help of the doctor, the district nurse, the pastor, social worker and given a favorable home atmosphere, a stable social situation, strong family ties, a basic acceptance of the patient, and genuine concern for his/her welfare, even the drawback of what might be considered serious physical inadequacies can be overcome. The rewards of successful home care are great and although we must be dissatisfied that a proportion suffer unduly in their terminal illness at home, the majority have reasonable care and their families consider that the dying have been adequately tended.<sup>27</sup>

It is interesting to note that, according to Glaser and Strauss,<sup>28</sup> the home is a more acceptable context for death in Europe and Asia than it is in the United States of America:

An American patient, when wishing to go home to die among familiar circumstances and companions, thinks twice about what he has to offer, for his trajectory at this stage may well be unacceptable to others at home. In America, he knows, dying persons are typically avoided even by kinsmen. Dying among family at home becomes only a valued abstraction. So he chooses to die on a ward where his trajectory is acceptable and where he is sheltered from possible rebuffs by his family. If conditions do permit his dying at home—his condition is not too repugnant; the family wants him, will not avoid him, and will take

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<sup>26</sup>Elizabeth R. Prichard, "Planning For the Terminally Ill Patient: The Social Worker's Responsibility," Journal of Thanatology, II:1-2 (1972)

<sup>27</sup>Hinton, Dying, p. 155.

<sup>28</sup>Glaser and Strauss, Time for Dying, p. 195.

the burden; his pain can be managed sufficiently well—the patient is likely to ask to die there. He will prefer this because dying at home gives him a greater chance to manage his own trajectory.

In cases where the family members are not able to care personally for the dying patient and need the assistance of a nurse or other help, it may still be impossible for the patient to go home because of the financial burdens. A registered nurse costs \$150 a day for twenty-four-hour home care, the fee for daily intensive-care nurses is \$231, and the most reasonable solution, a live-in home health aide, comes to \$189 a week.<sup>29</sup>

#### 4.3 Dying in a Nursing Home of an Old People's Community

With the great increase in the numbers of elderly people in our society, communities for the elderly are established in many places. The elderly in contemporary society are increasingly retired from gainful employment and other social activities. Because of the fact that many of them retreat to communities specially created for them to meet their specific needs, they are frequently less central to the lives of their families than were the elderly of the past. In this community for the elderly they establish new relationships and form new friendships.

Many of the communities<sup>30</sup> have special facilities for the caring of the terminally ill elderly member, and the person is not

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<sup>29</sup>Marya Mannes, Last Rights (New York: Morrow, 1974), p. 46.

<sup>30</sup>Pilgrim Place in Claremont, California is an example of such a community for the elderly.

rushed off to the local hospital and separated from a spouse and friends in a case of illness. In the nursing home the person can be cared for during the whole of their remaining life if need be. The elderly can feel reasonably secure that they will not be thrust out into some strange place where life is about to end. Because they become an "extended family" for each other there is an atmosphere of mutual trust and easy conversation. When a member of the community is hospitalized in their nursing home he/she is being taken care of by the professional staff and volunteer members from the community, still physically capable and eager to do something constructively. He/she is visited daily by his/her friends and his/her spouse, if alive. When a member of the community died, the word is passed round and there is a sense of mutual loss.

The nursing home surroundings are often more congenial to patients than those of a hospital. Fewer people are involved and there is an atmosphere of greater intimacy than that of a larger institution. Formality can be at a minimum without sacrificing any efficiency in nursing. Aspects of the hospital regime which are unhelpful to the individual patient can be dropped. Because of the atmosphere that exists, the size of the nursing home, the fact that the elderly person is known and respected as a person there is an honest attempt to establish communication between the patient and the staff. This will prevent the battles that can develop between staff and elderly patients who refuse certain treatments.

Unfortunately it is also true that sub-standard nursing homes like the poorer homes for the aged, can provide a half-concealed,

ill-tended shuffle from life. Ill and elderly people are often admitted to poorly staffed, poorly designed nursing homes at a time when the care they need can just about be managed. The isolation, plus the further stretching of limited resources in staff and equipment, may cause the dying more physical discomfort and mental distress than there should be, sometimes bordering on neglect.<sup>31</sup>

#### 4.4 Impact on Pastoral Care

The spiritual and religious dimensions of patient care are significant to the patient's well-being. Total patient care is significant to the patient's well-being whether the patient is at home, in a hospital or in a nursing home. Total care means meeting the patient's physical, psychological, spiritual and social needs at a given time and surroundings. These needs may differ from day to day and from place to place. The needs of the family may also differ from time to time and from place to place. The emotional needs of a wife whose husband is terminally ill and a patient in a modern hospital may be totally different when her husband returns home to spend his final days with his family and she has to take care of him. The alert, sensitive pastor will minister to the needs of each unique individual in each unique situation. In Part II I will discuss the pastoral care of the patient and the family in detail.

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<sup>31</sup>Hinton, Dying, p. 162.



## CHAPTER 5

### BIBLICAL PERSPECTIVES ON DEATH AND DYING

I do not intend to write a theology on death and dying; nor do I pretend to be exhaustive in my remarks about death in the Bible. Instead this is an attempt to present a few basic concepts which could be important and directive for those who, in their contact with the terminally ill patient and the family, choose to consider and discuss what is being said about death in the Bible.

It is important to realize that the pastor will not solely depend on these insights in his ministry to the dying. The pastor ministers to the patient in his/her totality and the Bible addresses the person in his/her totality.

It is the hope of the author that this chapter will be stimulating to the pastor/reader, taking him/her back to the Bible, the Word of God, to study and discover and in the process work out his/her own theology on death and dying.

#### 5.1 Death in the Bible

Death is a multi-faceted phenomenon. Not only does one's quest for the significance of one's ultimate earthly experience vary in approach—biological, philosophical, sociological or theological—but each person apprehends his own death in an unique way.<sup>1</sup>

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<sup>1</sup>Bernard Häring, Medical Ethics (Notre Dame: Fides Publishers, 1973), p. 121.

It is important to notice that it is impossible to speak about the Bible's view of death. The Old Testament records the historical and theological reflections of a People for over a millennium during which time considerable development and alteration of ideas are observable. The Bible itself has not wholly harmonized or integrated all of the ways in which death is spoken about by the variety of persons in the many lines and places in which the various scriptures were written.<sup>2</sup> Furthermore, the Biblical documents, as they are now preserved for us, are not individual responses to philosophical questions, but sustained sociological responses to the ever-changing events of history, through which Israel seeks to understand and maintain her identity. And this lack of sustained, systematic, thematic treatment suggests that death did not hold the terror for the Israelites that it does for us.<sup>3</sup>

Biological-medically speaking one can only define "death" when able to define "life" simultaneously. This is also true in the Bible where the concept of death is determined by insights about the meaning of life. When looking at the richness of information in Kittel's Theological Dictionary of the New Testament<sup>4</sup> about the concept of

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<sup>2</sup>Milton McC. Gatch, Death (New York: Seabury Press, 1969), pp. 35-36 and M. De Jonge, "De Dood in De Bijbel," in Heije Faber (ed.) Over Dood En Sterven (Leiden: Universitaire Pers, 1971), p. 54.

<sup>3</sup>Lloyd R. Bailey, "Death As a Theological Problem in the Old Testament," Pastoral Psychology, XXII (November 1971), 22.

<sup>4</sup>Gerhard Kittel (ed.) Theological Dictionary of the New Testament (Grand Rapids: Eerdmans, 1965), III, 7-21.

death (Thanatos) in the Old Testament as well as the New Testament we find a number of references to "Zaoo" (life) which is discussed in volume II.<sup>5</sup> It is only possible to discuss the Biblical concept of death if we conceptualize what "life" means according to the Bible.<sup>6</sup>

## 5.2 Biblical Concept of Life

The Old Testament "חַיִּים" does not cover all that we mean by "life." In Israel, generally, there was little religious interest in the origins of life. The ultimate source was known,<sup>7</sup> but far more important for the individual was the actual absolute relationship of his/her life to God. God is the Lord of life and death.<sup>8</sup>

Jawism regarded the actual event of dying as something caused directly by God Himself. This meant that the dead were excluded from fellowship with Yahweh and were in the highest degree unclean. We find in Ps. 88 a definition of the state of being dead which, theologically speaking, leaves practically nothing more to be said: The dead were cut off from praising Yahweh and from hearing Him proclaimed, and above all, they were cut off from themselves.<sup>9</sup> He

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<sup>5</sup>In Kittel, Theological Dictionary of the New Testament, II, 832-872.

<sup>6</sup>Jonge, "De Dood in De Bijbel," p. 55.

<sup>7</sup>Pss. 36:9; 139; 13ff.

<sup>8</sup>Nu. 27:16; Job 12:10; Dt. 32:39.

<sup>9</sup>Gerhard von Rad, Old Testament Theology (New York: Harper & Row, 1965), II, 349.

controls the book of life,<sup>10</sup> and since He was for Israel the One who had given it His covenant and direction, it naturally followed that the preservation or loss of life is decided by the attitude to His Word.

The possession of life is throughout the Old Testament an intrinsic good which cannot be relativised. It is indeed the supreme good. Wisdom offers riches and honor in the left hand, but long life in the right.<sup>11</sup> "All that a man hath will he give for his life."<sup>12</sup> In Israel the mere prolongation of physical life to ripe old age,<sup>13</sup> when a man dies old and full of years<sup>14</sup> is regarded as a special grace, and Deuteronomy sometimes holds out long life as the only reward for fulfillment of the divine commandments.<sup>15</sup> Similarly, the infinitely varied pursuit of wisdom simply has life or length of life as its goal.

In the New Testament, "ζωή" is first used of the natural life of man. Its opposite end is to be found in natural death.<sup>16</sup> It is corruptible.<sup>17</sup> It has limited extension in time.<sup>18</sup> It stirs and

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<sup>10</sup>Ex. 32:32; Mal. 3:16; Ps. 69:28; Isa. 4:3.

<sup>11</sup>Prov. 3:16.

<sup>12</sup>Job 2:4.

<sup>13</sup>Gn. 15:15; Jn. 8:32.

<sup>14</sup>Gn. 25:8; 35:29; Job 42:17.

<sup>15</sup>Dt. 5:16; 16:20; 30:19.

<sup>16</sup>Phil. 1:20; 2Tm. 1:10.

<sup>17</sup>Jn. 4:14.

<sup>18</sup>R. 7:1-3; Hb. 2:15.

moves.<sup>19</sup> It is actual in the ability of what is alive to do things. Thus, "to live," as in the Old Testament, can sometimes mean "to live in health."<sup>20</sup> Human life is sustained by nourishment.<sup>21</sup> The word of God sets man in decision between life and death.<sup>22</sup>

In Prov. 8:35,36 Wisdom addresses her audiences as a wisdom teacher might his/her pupils, urging on them the benefits to be derived from attentiveness to her words and warning against the perils attendant on neglecting discipline. It is a matter of life or death, of gaining or losing Yahweh's approval. The house of Wisdom is the gateway to life; that is those who submit to Yahweh's will and fulfill ultimate religious obligations (5:35b) will find life. Whereas those who miss life, love death and enter the threshold of sheol, is on a road to the underworld and it becomes a journey from which no traveler returns.<sup>23</sup>

"Ζωη" is proper to God as the "ζωv"<sup>24</sup> i.e., as not only the One who has life originately in Himself,<sup>25</sup> who lives eternally,<sup>26</sup> but

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<sup>19</sup>Ac. 17:28.

<sup>20</sup>Mk. 5:23; Jn. 4:50.

<sup>21</sup>Mt. 4:4; Lk 12:15; I Cor. 9:14.

<sup>22</sup>Prov. 8:35,36; Jer. 21:8.

<sup>23</sup>William McKane, Proverbs (Philadelphia: Westminster Press, 1970), p. 358.

<sup>24</sup>R. 9:26; Mt. 16:16; 26:63.

<sup>25</sup>Jn. 5:26.

<sup>26</sup>Rev. 4:9ff.

who can both make alive and kill.<sup>27</sup> God is Lord of Life and death,<sup>28</sup> as He is also Judge of the quick and the dead.<sup>29</sup>

### 5.3 The Meaning of Death

In the Bible death is described in terms of observable data. Phenomenologically, death quite simply means that a physical, or better, a psychosomatic-organism, a living being, whether plant or animal, ceases to function as such. To die is to come to an end, not so much the end of this life as the end life. Indeed, in both the Old Testament and the New Testament the word "destruction" is frequently a synonym for death.<sup>30</sup>

In the Old Testament the Israelites did not regard death as a separation of soul and body, as we, the heirs of Greek Tradition are accustomed to do. Death is to be explained in terms of life. They viewed it rather as the ultimate weakening and complete loss of all vitality. What remained of man in death was but a sort of shadow or ghost. Man loses this vital force with the last breath he exhales,<sup>31</sup> and it rises like a mist from freshly shed lifeblood, in which it is

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<sup>27</sup>R. 4:17.

<sup>28</sup>Lk. 12:20; 2Cor. 1:9.

<sup>29</sup>1 Pt. 4:5; Ac. 10:42.

<sup>30</sup>Fred D. Gealy, "The Biblical Understanding of Death," Pastoral Psychology, XIV (June 1963), 33.

<sup>31</sup>Job 11:20; Jer. 15:9.

thought to reside.<sup>32</sup> Connected with this is the concept that death is the cessation of breath.<sup>33</sup> Another concept which is found especially in the later books is that which considers life as the effect of the breath or spirit (ruah) of God; when God takes back His ruah, man and beast die.<sup>34;35</sup>

The common Old Testament view of death is a state of unconsciousness, forgetfulness and silence.<sup>36</sup> The present world is emphatically the land of the living.<sup>37</sup> Death is simply being gathered to one's fathers<sup>38</sup> who are now departed souls in the underworld or shoal.

Death is man's common fate, even shared by the beasts.<sup>39</sup> It is regarded as tragic primarily when premature or violent, but for one who has lived out his days in righteousness the realm of death may be regarded as well-earned rest.<sup>40</sup>

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<sup>32</sup>Lv. 17:11, 14.

<sup>33</sup>1 KGS. 17:17; Job 27:3.

<sup>34</sup>Pss. 104:29ff; 146:4; Job 34:14; Eccl. 12:7.

<sup>35</sup>Louis Hartman, Encyclopedic Dictionary of the Bible (New York: McGraw-Hill, 1963), pp. 532-533.

<sup>36</sup>Pss. 88:12; 94:17; 115:17.

<sup>37</sup>Pss. 27:13; 116:9.

<sup>38</sup>Jg. 2:10; 2K. 22:20.

<sup>39</sup>Pss. 49:10-12; 49:18-20; Ec. 3:20.

<sup>40</sup>Gn. 15:15; 25:8; Nu. 23:10; 1K. 2:6; Ps. 116:15; Jer. 34:41.

In a few instances death is described as non-existence or complete dissolution, "like water spilt on the ground."<sup>41</sup> Usually, however, death is the state of being in a very weakened state, with vitality and strength lost, and the soul (nephesh) either emptied out or escaped from the body.<sup>42;43</sup>

The inevitability and finality of death are taken for granted in most of the Old Testament. However, since the limitation of human life was set by Yahweh, He could allow certain rare individuals to escape death.<sup>44</sup>

Life and death, then, are not separate phenomena, but are bound together in a single process. To isolate the latter and rebel against it is to reject the former. Profound acceptance and appreciation for life can (though often does not) lead to the acceptance of its corollary. And the realization of the temporality of all things, of my gradual transition toward death, robs death of its potential as alien intruder.<sup>45</sup>

Thus, we can conclude that death is regarded as real, quite dreadfully real, that it is the annihilation of life conceived in its

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<sup>41</sup>2S. 14:14; Job 7:21; Ps 39:13.

<sup>42</sup>Gn. 35:18; 1K. 17:21; Isa. 14:10; Isa. 53:12.

<sup>43</sup>Grant and Rowley, Dictionary of the Bible (New York: Charles Scribner's Sons, 1963), p. 206.

<sup>44</sup>Gn. 5:24; 2K. 21:12.

<sup>45</sup>Bailey, "Death as a Theological Problem in the Old Testament," pp. 29-30.



concreteness, its potentiality for the enjoyment of the good earth, its rupture of the pleasures of family and friends, its destruction of the possibility of man's enjoying the pleasure and praise of God.

#### 5.4 The Meaning of "Sheol"

The dead end up in some kind of shadowy existence in Sheol; they are no longer alive; they are dead, but they exist.<sup>46</sup> Sheol, like the Babylonian "Arallu," is conceived as a place of darkness,<sup>47</sup> dust,<sup>48</sup> and corrupted.<sup>49</sup> It, too, is, at least by implication, the "land of no return."<sup>50</sup> It is a place of silence,<sup>51</sup> where, if the dead make any sound at all, it is only as the chirping of birds.<sup>52</sup> It is sometimes likened to a vast cemetery,<sup>53</sup> at other times to a great palace with gates and bars.<sup>54</sup> Common synonyms for Sheol are "grave," "pit," or "destruction." Sheol is located far off, at the nether

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<sup>46</sup>Randolph Crump Miller, Live Until You Die (Philadelphia: Pilgrim Press, 1973), p. 101.

<sup>47</sup>Isa. 59:10; Ps. 49:20; Job 10:20-22.

<sup>48</sup>Isa. 26:19; Pss. 22:16; 30:10; Job 17:16; 20:11; 30:19; Dan. 12:2.

<sup>49</sup>Isa. 14:11; Job 17:14.

<sup>50</sup>2S. 12:33; 14:14; Job 7:9; 10:21; Prov. 2:19.

<sup>51</sup>Pss. 31:18; 94:17; 115:17.

<sup>52</sup>Isa. 29:4.

<sup>53</sup>Isa. 14:20; Ezek. 32:18-32.

<sup>54</sup>Job 17:16; Isa. 38:10; Jonah 2:7; Ps. 9:14.

parts of the earth.<sup>55;56</sup> For Job in his despair Sheol seems almost inviting, but for a man in the vigor of life, it promises despair, for it represents the emptying out of life, the ultimate weakness whose partial experience, sickness turns man's days into sorrow.<sup>57</sup>

Did Yahweh have dominion over death and Sheol? The answer must be a resounding "yes"! Yahweh is said to have "created" the nether world<sup>58</sup> and it is "naked" before him.<sup>59</sup> His wisdom is deeper than Sheol<sup>60</sup> and He leads the shadow of death to light.<sup>61</sup> Yahweh's power over death may also be seen in the fact that death is ultimately attributed to Him. It is Yahweh who kills or keeps alive. It is true that the "power" of the underworld can kill, but in all cases this happens only when Yahweh wills it.

Death begins to become a reality at the point where Yahweh forsakes a man, where He is silent, i.e., at whatever point the life-

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<sup>55</sup>Dt. 32:22; Isa. 44:23; 57:9.

<sup>56</sup>Andrew F. Key, "The Concept of Death in Early Israelite Religion," Journal of Bible and Religion, XXXII:3 (1964), 241.

<sup>57</sup>Lou H. Silberman, "Death in the Hebrew Bible and Apocalyptic Literature," in Liston O. Mills (ed.) Perspectives on Death (New York: Abingdon Press, 1969), p. 21.

<sup>58</sup>Pss. 33:7; 95:4.

<sup>59</sup>Job 26:6; Prov. 15:11

<sup>60</sup>Job 11:7-8.

<sup>61</sup>Job 12:22.

relationship with Yahweh wears thin. From there it is only a step till the final cessation of life.<sup>62</sup>

#### 5.4 Is Death Natural or Unnatural?

The amazing thing about the attitude towards death, given the rather forbidding belief about the underworld, Sheol, is that we find among the Israelites a more or less "passive acceptance" of the fact that all die and that death is to be accepted as "natural." The length of a person's life is a more or less accurate barometer of his moral worth, and yet, even this belief was not expanded into any assertion that one could be saved from death itself by right action. According to Vriezen,<sup>63</sup> "only the author of Genesis 2f. looked upon death as a punishment, but for the rest, 'the worst enemy,' is accepted as a natural phenomenon."<sup>64</sup>

The Jewish and Christian traditions describe time as movement in a definite direction, not merely cyclical. Therefore, man's existence moves toward an end.<sup>65</sup> Man knows he belongs to time: "The years of our life are three score and ten."<sup>66</sup> He knows that like the

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<sup>62</sup>Rad, Old Testament Theology, I, 388.

<sup>63</sup>T.C. Vriezen, An Outline of Old Testament Theology (Oxford: Blackwell, 1958), p. 310 and Ps. 90:1-12.

<sup>64</sup>Key, "The Concept of Death . . . ," p. 247.

<sup>65</sup>Sam A. Banks, "Dialogue on Death: Freudian and Christian Views," Pastoral Psychology, XIV (June 1963), 44.

<sup>66</sup>Ps. 90:10.

grass of the field he is one whose place knew him no more.<sup>67</sup> Only God is from "everlasting to everlasting."<sup>68</sup> Only God has life in himself.<sup>69,70</sup> A fundamental issue is developing a theology of death centers on the question whether death is a natural or unnatural event. This question has been a point of discussion for many years. Theologians like Louis Berkhof<sup>71</sup> and Helmut Thielicke<sup>72</sup> claim that death is an unnatural, abnormal event, that which is opposed to God and his purposes. On the other hand, theologians P.J. Van Leeuwen,<sup>73</sup> Karl Barth<sup>74</sup> and Karl Rahner<sup>75</sup> place a renewed emphasis on the importance of recognizing man's finitude as a basic element in being human.

#### 5.6 Jesus Christ and Death

Christ says nothing about death as a physical phenomenon. He makes no attempt to explain what death will be like nor to answer the

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<sup>67</sup>Ps. 103:16.

<sup>68</sup>Ps. 90:2.

<sup>69</sup>John 5:26.

<sup>70</sup>Gealy, "The Biblical Understanding of Death," p. 35.

<sup>71</sup>Louis Berkhof, Systematic Theology (Grand Rapids: Eerdmans, 1959)

<sup>72</sup>Helmut Thielicke, Death and Life (Philadelphia: Fortress Press, 1970)

<sup>73</sup>P.J. Van Leeuwen, as quoted in G.C. Berkhouwer, Man: The Image of God (Grand Rapids: Eerdmans, 1962)

<sup>74</sup>Karl Barth, Church Dogmatics (Edinburgh: Clark, 1960), III/2

<sup>75</sup>Karl Rahner, On the Theology of Death (London: Burns & Oates, 1961)

questions that have always excited man's curiosity.<sup>76</sup> Death is looked upon as a fact and a grim reality which must be confronted without evasion or suppression. This came from the "naturalness" and the closeness of death in the life of the Hebrews. They believed in their earliest thoughts that only death could separate man from God. Christ demonstrates that he not only is Lord of life but also has power over death, man's last enemy.<sup>77</sup>

Christ first proclaims that He is the resurrection and the life. No person will possess life unless he is first rescued from the dead. Christ teaches that He is the beginning of life. "If a man has faith in me, even though he die, he shall come to life." Through His spirit Christ regenerates people who by their sin were alienated from God, so that they will begin to live a new life. Therefore, those who believe in Christ, although they had before been dead (spiritually) will begin to live unto God.

What is crucial is that Jesus has given physical life to Lazarus, as a sign of His power to give eternal life and as a promise that on the last day He will raise the dead.<sup>78</sup>

There is throughout the life and teachings of Jesus the concept that he must die in order to fulfill his mission and purpose. The New Testament strongly asserts that Jesus died a real death. It

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<sup>76</sup> Grant and Rowley, Dictionary of the Bible, p. 205.

<sup>77</sup> Jn. 11:1-53.

<sup>78</sup> Jean Calvin, The Gospel According to St. John (Grand Rapids: Eerdmans, 1961), pp. 1ff.

was a death which Jesus feared because He, who walked so close to God, would now come into the hands of the demonic and it was this separation that was so terrifying. Death for Jesus was the consummation of His life, and it was only through his death that He could offer man any hope for the future. He defeated death through His own death and hence changed Its nature and power.<sup>79</sup>

The view of death as something evil and unnatural had therefore no place in the thoughts of Jesus. He nowhere suggests the idea which Paul took over from the Old Testament and elaborated in his Theology; that death is the punishment of sin. Jesus insisted that death, even when it comes prematurely and violently is not to be regarded as a Divine judgment.<sup>80</sup>

Sin is punished, not by physical death in this world, but by a spiritual death hereafter. While thus regarding death as nothing, but one of the incidents in man's earthly existence, our Lord anticipates a time when it will be done away. In the perfected Messianic Kingdom "they cannot die any more."<sup>81</sup>

### 5.7 Death, Sin and Finitude

The apostle, Paul, linked sin and death in his thinking.

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<sup>79</sup>Douglas T. Holden, Death Shall Have No Dominion (St. Louis: Bethany Press, 1971), pp. 53-55.

<sup>80</sup>Lk. 13:1-4.

<sup>81</sup>Lk. 20:36.

Death is the consequence and punishment of sin.<sup>82</sup> He regards sin as a responsible act and death as its consequence.<sup>83</sup> It is clear that Paul is not attributing sin to something which is not sin (e.g., matter, sensuality, etc.), but that he is saying that death came into the world through sin, and that Paul in his preaching has in view only men who are responsible for their sin and therefore for their death.<sup>84</sup>

In his commentary on Rom. 5:12 Karl Barth says that death is engraved inexorably and indelibly upon our life. Through sin, death entered into the world. It entered the world as a result of the original and invisible sin by which the life, which is the relationship of men to God was damaged. Sin is guilt, and the destiny of sin and guilt is death. Adam is the one through whom death entered the world. For he committed the invisible sin and fell from God. We see all men doing what Adam did, and then suffering as Adam suffered. We see men sin and then die.<sup>85</sup>

We have to ask a highly speculative, but intriguing theological question: If man had never sinned, if he had never fallen, would there be no death in the world? It is true that Christian

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<sup>82</sup>R. 1:32; 6:16; 6:21,23; 7:5; 8:6,13; 1Cor. 15:56; Jn. 1:15.

<sup>83</sup>R. 5:12ff.; 1Cor. 15:21f.

<sup>84</sup>Gerhard Kittel (ed.) Theological Dictionary of the New Testament (Grand Rapids: Eerdmans, 1965), III, 15-16.

<sup>85</sup>Karl Barth, The Epistle to the Romans (London: Oxford University Press, 1960), pp. 164ff.

theology has been almost exclusively pre-occupied with the Old Testament story that connects sin and death, and has given little thought to the relation of finitude and death. Even if there had been no sin, would there not still be an end, which we may call "death," for any finite, embodied existence in the world? It is true that for one who had not sinned there would be no necessity to die, or is it not more likely that for such a one also there would come an end or death? For we can hardly suppose that such a person would live forever in the world—indeed, even the world itself does not last forever.<sup>86</sup>

The question of sin, finitude and death has been discussed by Karl Rahner.<sup>87</sup> He says:

It is not legitimate to infer from this proposition of faith that the first man in paradise, had he not sinned, would have lived on endlessly in his life. Rather, it can be said with certainty that he would surely have experienced an end of his life, but in another manner.

The relationship between sin and death, according to Von Rad,<sup>88</sup> is that man becomes fully aware of the significance of his mortality as a result of sin.

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<sup>86</sup> John Macquarrie, "True Life in Death," Journal of Bible and Religion, XXXI:3 (July 1963). 204.

<sup>87</sup> Karl Rahner, "The Theology of Death," in A.R. Caponigri (ed.) Modern Catholic Thinkers (London: Burnes and Oates, 1960), p. 152.

<sup>88</sup> Gerhard Von Rad, Genesis (Philadelphia: Westminster Press, 1961), p. 92.



It is not physical death that is the result of sin, but the fact that men fear life and death and the future. This is the de-humanizing power of death.

#### 5.8 Death Defeated

Death as a destroying power is thus superseded over human life and there is no evading it outside revelation. But in revelation, i.e., through Christ, God has destroyed death.<sup>89</sup> Christ's death and resurrection are the eschatological event. His death differed from the ordinary lot of men. It was the death which God caused Him to die for us. It was not His debt to sin. God made Him to be sin for us and He was condemned as such.<sup>90</sup> Hence He died for us.<sup>91</sup> God deals with the world through Christ,<sup>92</sup> and that, inasmuch as in this action God took death to Himself in Christ, it lost its destructive character and became a creative divine act. Thus, the resurrection is grounded in Christ's death. This death removed sin and it therefore removed death.<sup>93</sup> Life grew out of it. Death is overcome for those who make this death their own in faith.

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<sup>89</sup>2Tm. 1:10; HB. 2:14.

<sup>90</sup>2Cor. 5:21; R. 8:3.

<sup>91</sup>R. 5:6; R. 5:8; 2Cor. 5:21; GL. 3:13; Eph. 5:2; 1Jn 3:16; etc.

<sup>92</sup>2Cor. 5:19.

<sup>93</sup>Rom. 6:7-10; 8:3.

Believers are still subject to physical death, though in the early days of imminent expectation of the parousia it is seen that this fate will not overtake all Christians.<sup>94</sup> The destruction of death will come with the resurrection or with the change which comes with the parousia. When the expected events of the last time are completed, there will be no more death.<sup>95</sup> Even now death has lost its sting for believers. They already have the victory.<sup>96,97</sup>

Salvation and the victory over death consist in "being again able to love." But this is first of all a relation to Christ. Only when I recognize, lovingly, what He has done for me, does my life become again meaningful. Only in the fact that He died in his particular way lies the possibility that at the end, at my death, something has become worthy of God's love, for Christ's sake and yet in me. Thus, my deed, my living and dying, is not primarily related to me but to Him.<sup>98</sup>

Karl Barth writes that there is no such thing as life in itself. There is only life in relation to God. That is to say, there is only life under His judgment and under His promise; There is only

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<sup>94</sup>Mk. 9:1; 1Th. 4:15ff.; 1C. 15:51f.

<sup>95</sup>1Cor. 15:26; Rev. 21:4.

<sup>96</sup>1Cor. 15:55.

<sup>97</sup>Gerhard Kittel (ed.) Theological Dictionary of the New Testament (Grand Rapids: Eerdmans, 1965), III, 18.

<sup>98</sup>Wilhelm Breuning, "Death and Resurrection in the Christian Message," in Johannes Wagner (ed.) Reforming the Rites of Death (New York: Paulist Press, 1968), p. 20.

life characterized by death, but qualified, through the death of Christ, as the hope of life eternal.

To be strong means to fear and to love God above all things. To fear and to love Him as the Lord. If one knows that one lives unto the Lord and dies unto the Lord, one acknowledges thereby that both one's life and one's death, one's "yes" and one's "no" can claim no other justification side by side with the justification that God alone can bestow upon one.<sup>99</sup>

One's life and death being through the fact of faith at the Lord's service, the contrast between living and dying is thus completely dependent on the higher direction impressed on one's being. For the believer, to live is to serve Christ; to die, is to be united to Him more perfectly.<sup>100</sup> Hence it follows that one remains in every case the Lord's property. One no longer bears the care for oneself, for one's own life, but lets this care go, yielding oneself entirely to the grace of God, and lives for God, in life and in death.<sup>101</sup>

None of us lives to himself, and none of us dies to himself. If we live, we live to the Lord, and if we die; we die to the Lord; so then, whether we live or whether we die, we are the Lord's. For to this end Christ died and lived again, that He might be Lord both of the dead and of the living.<sup>102</sup>

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<sup>99</sup>Barth, Epistle to the Romans, pp. 512-513.

<sup>100</sup>F. Godet, Commentary on St. Paul's Epistle to the Romans (New York: Funk and Wagnalls, 1883), pp. 457ff.

<sup>101</sup>Rudolf Bultman, Theology of the New Testament (New York: Charles Scribner's Sons, 1951), I, 330-331.

<sup>102</sup>Rom. 14:7-9.

## **PART II**

### **DYNAMICS**

## CHAPTER 6

### THE TERMINALLY ILL CHILD

#### 6.1 Development of the Concept of Death in the Child

Because we no longer live in a time when infant and child mortality is an accepted part of our immediate daily life we are affronted when it happens. Death is increasingly the experience of the elderly and it happens in hospitals and institutions.<sup>1</sup> A century ago no child grew up without the edification of at least one deathbed scene, death was very much a part of life. When we have to, we discuss death privately in hushed tones. We try not to think about it and we do not know our feelings and attitudes about death and dying. Because of our own uncomfortableness with death we fail to educate our children about death. When we can no longer avoid the reality of death and it enters our home or our community we do not take an especially healthy approach to explaining death to our children. It has been suggested that most parents either believe or use as an excuse, the misconception that children have no notion of death, and that they therefore need no reassurance on the subject.<sup>2</sup>

Whether or not we talk and explain death to children, it is something that they learn. They observe friends and families'

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<sup>1</sup>See Chapter 3.

<sup>2</sup>Richard Dumont et al., The American View of Death (Cambridge: Schenkman, 1972), p. 12.

reactions as they face death and loss. They learn from daily experiences. A funeral procession passes by. A pet dies. An innocent question is raised at the dinner table: "Was this meat once a real live cow?" The child is brought in contact with death by the mass-media: television, newspapers and picture magazines. They taste real death and real reactions to it—sometimes presented in a most melodramatic way.

The gradual accumulation of information that becomes the child's concept of death is a developmental process which markedly coincides with his maturational process. For this reason I will examine and discuss the concept of death in four developmental periods: the infant and the toddler period includes the first three years of life; the preschool period refers to the child from ages three to six; the latency age period considers the child up to about the age of ten; and the last period deals with the preadolescent and adolescent. Schowalter<sup>3</sup> uses these four developmental periods as a convenient way for the consideration of this material and he warns: "these attitudes and concepts do not change abruptly at a given age but evolve gradually and with wide individual variation."<sup>4</sup>

In our understanding and helping of the terminally ill child and the family it is necessary to know what death means to the dying

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<sup>3</sup>John E. Schowalter, "The Child's Reaction to His Own Terminal Illness," in Bernard Schoenberg (ed.) Loss and Grief (New York: Columbia University Press, 1971)

<sup>4</sup>Ibid., p. 52.

child and how she/he understands it. There is no way to predict a child's response to his/her own impending death. Knowledge about the development of the concept of death may help an adult to understand the terminally ill child better and to respond in an appropriate way to the unique needs of each child.

#### 6.1.1 The Infant and Toddler

During the first six months of his life the infant does not experience himself as separate from the world around him. He is totally dependent on someone else (usually his/her mother) for nurturing and survival. The baby comes to have a sense of being and non-being as she/he wavers back between wakefulness and sleep.<sup>5</sup> Death for him/her is a physical process and his/her inner physiological sensations stimulate his physical organism to fight for survival. Easson<sup>6</sup> refers to this process as the "death agony," meaning the physically based, nightmarish sensations with none of the psychological aspects that accompany death in the older child.

By the time she/he is three months old, the healthy baby is secure enough to experiment with the contrasting states of being and non-being. In the game of peek-a-boo, she/he replays in safe circumstances the alternate terror and delight, confirming his/her sense of

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<sup>5</sup>Adah Maurer, "Maturation of Concepts of Death," Journal of Medical Psychology, XXXIX (March 1966), 35.

<sup>6</sup>William M. Easson, The Dying Child (Springfield, IL: Thomas, 1972), pp. 6-7.

self by risking and regaining complete consciousness. To the empathetic observer, it is obvious that the baby enjoyed the temporary dimming of the light, the blotting out of the reassuring face and the suggestion of a lack of air which his/her own efforts enabled him/her to restore, his/her aliveness additionally confirmed by the glad greeting and the recognition implicit in the eye to eye oneness with another human. It is interesting that, etymologically peek-a-boo stems from Old English words meaning "Alive or dead?"<sup>7</sup> Awareness of being and non-being is thus the first of a series of adaptations to the fact of a finite life.

Babies, a few months older begin to delight in disappearance-and-return games. Overboard goes a toy, somebody fetches it, then overboard again. The questions: "When is something gone?" and "When is it gone 'forever'?", seem very important to the young explorer.<sup>8</sup>

But all things do not return. By one year most children understand the phrase "all gone!" and learn to say it among their first combinations, when the plug is pulled bathwater becomes "all gone" and rare is the child who does not fear, at least at first, that he/she will go down with it. Feces disappear down the plumbing. Where did it go? When the child begins to suspect that all things do not

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<sup>7</sup>Maurer, "Maturation of Concepts of Death," p. 36.

<sup>8</sup>Robert Kastenbaum, "The Kingdom Where Nobody Dies," Saturday Review, LV (December 23, 1972), 38.



return, he attempts mastery of his fears of disappearance in another way. He learns to project "all gone," and produce it at will.<sup>9</sup>

Eissler<sup>10</sup> states that the knowledge of time is necessary for the knowledge of death. "If man could not experience time, he could never fathom death, which would then be as meaningless to him as it is to the animal."

The toddler does not yet know death—only absence. Since this concept of time is still faulty and incomplete, any departure is viewed as an abandonment. If the mother is not frequently present in the hospital, the dying child experiences only a rotation of nurses who come, then leave, thus aggravating his/her terror. It may be paraphrased that toddlers may die many times before their deaths, while the older child need taste death but once.<sup>11</sup>

Nagy's<sup>12</sup> study with 378 children in Budapest, done in 1948, is one of the few reports of children's attitudes toward death. She has dealt with the developmental features of these attitudes for she hypothesizes that the adult outlook on death begins to take its basic form in childhood. Stage one in her study considers the child who is under five years old. The child (3-5 years) does not know what death

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<sup>9</sup>Maurer, "Maturation of Concepts of Death," pp. 36-37.

<sup>10</sup>Kurt R. Eissler, The Psychiatrist and the Dying Patient (New York: International Universities Press, 1973), p. 265.

<sup>11</sup>Schowalter, "The Child's Reaction . . .," p. 54.

<sup>12</sup>Maria H. Nagy, "The Child's View of Death," in Herman Feifel (ed.) The Meaning of Death (New York: McGraw-Hill, 1965), pp. 79ff.

is and denies death as a regular and final process. To him death is like sleep: You are dead, then you are alive again; or like taking a journey: You are gone, then you come back again. She/he attributes to the dead life and emotions, but in a different situation.

B. I. (4, 11): 'What happens there under the earth?'  
 'He cried because he is dead.'  
 'But why should he cry?'  
 'Because he is afraid for himself.'<sup>13</sup>

The most painful thing about death is the idea of separation. Most children, are not satisfied when someone dies that she/he should merely disappear, but want to know where and how she/he continues to live.

F. R. (9, 11): 'I was six years old. A friend of my father's died. They didn't tell me, but I heard. Then I didn't understand. I felt it was like when mother goes traveling somewhere—I don't see her any more.'<sup>14</sup>

#### 6.1.2 The Preschool Child

As the horizon of the child's world widens (4-5 years) and she/he goes out to begin associations with other people, she/he begins to understand that death is something which happens to other people. A grandmother dies, or a pet cat is killed. The idea of death is still vague and associated with sleep and the absence of light and movement, but it is not yet seen as permanent. Death is comprehended as the opposite of life and life is full of energy and movement.

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<sup>13</sup>Ibid., p. 82.

<sup>14</sup>Ibid., p. 83.

Death then, is the absence of movement. Death still remains separation, but the child is now able to understand short separations from those she/he loves, so death must now take on other dimensions. Children at this age respond more spontaneously and with less anxiety to questions about death than at other ages, maybe because they do not comprehend its permanency or personal relevance.<sup>15</sup> Nagy<sup>16</sup> incorporates the pre-school child in her study into her Stage I. Within this stage she differentiates between the younger and older children by describing the older members of the group as beginning to see death more realistically. They are still unable to accept death as a definitive fact. They acknowledge that death exists, but think of it as a gradual or temporary thing.

L.B. (5, 6): 'His eyes were closed.'  
 'Why?'  
 'Because he was dead.'  
 'What difference is there between sleeping and dying?'  
 'Then they bring the coffin and put him in it. They put the hands like this when a person is dead.'  
 'What happens to him in the coffin?'  
 'The worms eat him. They bore into the coffin.'  
 'Why does he let them eat him?'  
 'He can't get up any longer because there is sand on him. He can't get out of the coffin.'  
 'If there were no sand on him could he get out?'  
 'Certainly, if he wasn't very badly stabbed. He would get his hand out of the sand and dig. That shows that he still wants to live.'<sup>17</sup>

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<sup>15</sup>Nancy Doyle, "The Dying Person and the Family," Public Affairs Pamphlet, No. 485 (1972), 16.

<sup>16</sup>Nagy, "The Child's View of Death," p. 84f.

<sup>17</sup>Ibid., p. 85.

L.B.'s conversation is a mixture of fact and fantasy. During this stage death is often associated with violence and the child fantasizes around death. We tend to attribute the violence to television watching, but it appears to be more than that. Not only can it be observed in the children Nagy studied, but it is also seen in the literature.

The child's emotional involvement with death characteristically takes the form of fear of death.<sup>18</sup> This fear is manifested in a line from the oldest known and most popular children's prayer:

Now I lay me down to sleep  
I pray Thee, Lord, my soul to keep  
If I should die before I wake  
I pray Thee, Lord, my soul to take.

Not very long ago, my little boy, now four years old, called me during the night and told me that he could not sleep. I asked him what makes it difficult for him to sleep. He answered: "I am afraid to close my eyes, for when I close my eyes I may die . . . ." For him death is like going to sleep and he certainly does not want to die.

Schowalter<sup>19</sup> emphasizes that guilt is often almost as common as fear during this stage. When illness and other misfortunes come the child often relates them to his behavior and sees what is happening as his/her punishment. Parents are often unknowingly responsible for this view. They say to the child: "Something will

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<sup>18</sup>Dumont, The American View of Death, p. 10.

<sup>19</sup>Schowalter, "The Child's Reaction . . . ," p. 56.

happen to you if you are not a good boy" or "if you don't do as I tell you!"

It is important to remember that it is typical for children during this stage to ask about death and dying. It is at this point that a child perceives that his/her questions about death can comfortably be handled by his parents, or, conversely, that this is a subject they would prefer not to discuss. "You are too young to understand," is a statement, in one form or another, that commonly conveys the latter preference. Thus, the child may learn that it is O.K. to talk about death or that death is not a subject for general conversation.<sup>20</sup>

#### 6.1.3 The Early School-Aged Child (6-10 years)

This period begins with the child's entrance into an expanded social and industrial world of the schoolroom where she/he begins to use and to test all that she/he had learned in the seclusion of his/her family and immediate neighborhood.

The early years coincide with Nagy's Stage II<sup>21</sup> in which the children interviewed generally personified death. Death is sometimes seen as a separate person—for example, an angel or a frightening clown. For other children death is represented by a dead person. Death usually makes his rounds in the night. The big shift in the

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<sup>20</sup>Stanford B. Friedman, "Management of Death of a Parent or Sibling," in Morris Green (ed.) Ambulatory Pediatrics (Philadelphia: Saunders, 1968), p. 780.

<sup>21</sup>Nagy, "The Child's View of Death," p. 97.

child's thinking from stage one is that death now seems to be understood as final: it is not just a reduced form of life. But there is still an important protective feature here: personal death can be avoided. Run faster than the Death Man, lock the door, trick him, and you will not die, unless you have bad luck.<sup>22</sup> As Nagy<sup>23</sup> puts it, "Death is still outside us and is not general."

Studies by Piaget and Safier of children in this age group substantiate Nagy's findings. Children attribute death to an external cause which results in something happening to people.<sup>24</sup>

According to Kimball<sup>25</sup> the child during this stage has an active fantasy life dealing with violence and aggression which is both verbal and pictorial. Children at this age may become preoccupied with death and killing, but these preoccupations are usually at a great distance from their own lives in terms of actuality and reality. The active life and death game as embodied in "Cowboys and Indians" or "Cops and Robbers" puts the concept of death—the falling down with the hand over the mortal wound—into one more consistent with adult concepts.

During these years the permanency and universality of death gradually, if incompletely, make their impact on the child. Death in

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<sup>22</sup>Kastenbaum, "The Kingdom Where Nobody Dies," p. 38.

<sup>23</sup>Nagy, "The Child's View of Death," p. 98.

<sup>24</sup>Schowalter, "The Child's Reaction . . . ," p. 58.

<sup>25</sup>Chase Patterson Kimball, "Death and Dying: A Chronological Discussion," Journal of Thanatology, I:1 (January-February 1971), 44.

old age is grasped first. The unnaturalness of childhood death is also first understood at this age.

Although there are a few recorded case histories of children at three and four knowing that they were dying, anticipation of his/her own death to the dying child is rare before his fifth or sixth year. The frequency begins to rise from the sixth year reaching almost 100% in late adolescence. It is frequently towards the end of this stage, the latency period, when children begin to ask questions about the seriousness of their condition when they are ill, and if they might die.<sup>26</sup>

#### 6.1.4 Pre-Adolescence and Adolescence (10-20 years)

Along with the struggle to determine his/her ego identity, the adolescent wrestles with the problem of occupational identity. She/he begins to make active choices for what she/he wants from the complex and conflicting possibilities which stretch before him/her.

It is doubtful whether an individual can fully conceive the fact of his/her own death. Yet, during this stage, the fact of the universality and permanence of death finally does become comprehensible.<sup>27</sup>

"I will die" can now be said by the adolescent, for she/he is now far enough along in his/her development to think in abstract

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<sup>26</sup>Schowalter, "The Child's Reaction . . . ," p. 59.

<sup>27</sup>Ibid., p. 61.

concepts. Death now is an universal fact and she/he, as a member of the human race, is not excluded. In contemplating his/her future she knows it contains his/her own personal death. What she/he does not know is when and how it will happen.

According to Nagy's study,<sup>28</sup> Stage III, the ability to understand death as an individual process, operating within everyone, begins at the age 9 or 10 and continues into the adolescent period.

Since the child now has an almost adult capacity to understand death, his/her response to terminal illness is more like that of the adults in his/her culture. The adolescent must cope with vast bodily changes as well as redirect intensified sexual impulses toward appropriate objects outside the family. The task is an enormous and frightening one even under the best of circumstances. For the terminal adolescent, however, it soon becomes apparent that the changes in one's body will prove not to be a vital asset to one's fulfillment, but a fatal liability. While all patients should be kept informed of the physical side reactions to treatment, this is particularly important in the care of adolescents.<sup>29</sup>

Sooner or later most children come to understand that death is final, universal and inevitable. Parents might prefer that children remain innocent of what is happening in their lives and sheltered from emotional stress, shock and anguish. But it is our own make-believe,

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<sup>28</sup>Nagy, "The Child's View of Death," p. 98.

<sup>29</sup>Schowalter, "The Child's Reaction . . . ," pp. 61-62.



not theirs, if we persist in behaving as though children are not attuned to the prospect of mortality. It is important to remember that in this century millions of children around the world have grown up literally in the midst of death and the threat of death. They have fewer illusions on the subject than do many adults.<sup>30</sup>

Children welcome the opportunity to talk about death and dying at their own level. The problem then, is an adult one. We set up restrictions to protect ourselves from our fears. We have difficulty accepting death as part of life. When a friend's rabbit was found dead in the morning, the mother quickly disposed of the dead rabbit, and told the children, age 5 and 3, that the rabbit ran away during the night. This mother had missed an excellent opportunity to explore the idea of death with her children, on their level, answering their questions honestly and sincerely. In this way a fearful unknown subject could be explored in the safety of the warm loving relationships within the family.

## 6.2 The Psychology and Needs of the Terminally Ill Child

The death of a child is one of the outrages of nature. The basic efforts of childhood are toward completing development by attaining physical and emotional mastery of the self and the environment. For the dying child, this effort is rudely thwarted. Instead

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<sup>30</sup>Kastenbaum, "The Kingdom Where Nobody Dies," p. 38.

of mastery, there is failure. Instead of growth, there is wasting. Instead of joy, there is grief.<sup>31</sup>

Extended dying, over months or years, is now much more common in childhood than it was several decades ago. With expert medical and surgical care, sometimes the child may survive the immediate injury of an accident but linger crippled and disfigured to die more gradually over a lengthy period. The congenitally handicapped child, who formerly would have died at birth or in early infancy, now survives with medical care to an older age and succumbs over an extended time. The youngster with a malignant tumor is now kept alive for many more weeks or months by the use of intensive medical palliative procedures and by multiple surgical interventions. The leukemic child continues to live through a lengthy period of transfusions and drug treatments and therefore takes much longer to die. The chronic nephritic adolescent can be kept alive only with the help of repeated renal dialysis procedures. Death is delayed because the teenager is attached to this machine at frequent intervals. A kidney transplant may extend the life of this child and thus his process of dying. The child with cystic fibrosis is likely to survive infancy but is still liable to die slowly over months or years after a series of multiple lung infections. Dying in childhood now tends to be more prolonged and much more obvious. With many children, advances in the diagnosis and the treatment of illness have postponed death but at the cost of

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<sup>31</sup>Schowalter, "The Child's Reaction . . . ," p. 51.

extending the process of dying and subsequently the emotional trauma for those involved.<sup>32</sup>

Cancer is the leading cause of death from disease in children from one to fourteen years. The American Cancer Society estimates that 40% of these children have a diagnosis of leukemia, and that another 25% have a type of cancer which involves the brain and the central nervous system. For these reasons, childhood cancer has the impact of a death sentence.<sup>33</sup>

When the dying patient is a child, surrounding circumstances seem exceedingly more complex and more painful for all involved.<sup>34</sup> The child's death seems most unnatural and unnecessary. In Carl Jung's words, it is "a period placed before the end of the sentence," sometimes when the sentence has hardly begun.<sup>35</sup>

#### 6.2.1 The Trauma of Hospitalization

If going to the hospital means leaving the care of one's mother (which it usually does) this is inevitably an intensely unhappy

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<sup>32</sup>Easson, The Dying Child, p. 4.

<sup>33</sup>Dorris S. Potter, "Specific Problems Related to the Age of the Child," in American Cancer Society, Proceedings of the National Conference on Cancer Nursing (New York: 1974), p. 53.

<sup>34</sup>Domeena C. Renshaw, "The Dying Child," in Sarah Sheets Cook (ed.) Children and Dying (New York: Health Sciences, 1974), p. 20.

<sup>35</sup>Joseph Bayly, The View From a Hearse (Elgin, IL: Cook, 1971), p. 50.

experience for the small child—no matter how kindly she/he is cared for by the doctors and nurses.<sup>36</sup>

The small child is very intensely and almost exclusively attached to the mother. Being taken to a hospital, undressed and being put into a strange bed in a strange unknown environment is a traumatic experience. Usually after some time the mother has to leave and the "people in white" move in. The child experiences feelings of anxiety, insecurity and fear. During this time when the child needs the loving care and encouraging presence of the people he trusts and loves more than ever, hospital rules and authorities reduce the child's access to the mother (parents) significantly. (Because of the results of research done in this area, efforts have been made to counteract this undesirable effect of hospitalization by liberalizing visiting hours and by the development of programs for parent participation as part of hospital pediatric services. Unfortunately these hospitals are still by far in the minority.<sup>37</sup>

Anna Freud goes beyond usual discussion of the separation anxiety experienced by the child which occurs when hospitalization takes place. She emphasizes the change in parental emotional climate during illness so that the child experiences unexpected handling such as deception, forced feeding, or forced bowel evacuation. The child

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<sup>36</sup>James Robertson (ed.) Hospitals and Children (New York: International Universities Press, 1962), p. 13.

<sup>37</sup>Alfred G. Knudson and Joseph M. Natterson, "Practice of Pediatrics—Participation of Parents in the Hospital Care of Fatally Ill Children," Pediatrics XXXVI:3 (1960) Part I.

may react to such unexpected handling by feeling helpless and bewildered because she/he notices that formerly "immovable emotional and moral standards" are broken. The experience of being nursed may be harmful to children who, because of their early stage in life, have recently been mastering various bodily functions. Nursing in which the child is fed, cleaned and assisted with excretory activities, his/her nakedness on view, is experienced as a loss of control in a variety of areas in which she/he has only recently learned control, with resultant pull toward earlier and more passive levels of development.<sup>38</sup>

The anxiety and trauma is often increased by the placement of children in hospitals. In my experience as hospital chaplain I was at times stunned and shocked as to where children were placed in hospitals! A mother reports about her little boy ( $\pm$  3 years old.) "His cot was in a corner next to an old man, who had been under a fall of bricks. He was a grotesque sight for a child, bruised and bandaged and quite unable to speak to a child."<sup>39</sup> Robert Toch<sup>40</sup> favors the general pediatric ward as best suited for terminally ill youngsters, unless special needs are better met in an intensive care unit. Special wards are a convenience for the medical personnel, but are most

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<sup>38</sup> Gilbert Kliman, Psychological Emergencies of Childhood (New York: Grune And Stratton, 1968), p. 13.

<sup>39</sup> Robertson, Hospitals and Children, p. 91.

<sup>40</sup> Rudolf Toch, "Too Young to Die," in Bernard Schoenberg (ed.) Psychosocial Aspects of Terminal Care (New York: Columbia University Press, 1972), p. 69.

traumatic psychologically for the older child. These wards may help the parents, since it gives them a chance to share their sorrow with other parents of dying children, but the patient tends to identify with older patients and, unless an elaborate system of deception is practiced, the patient will draw often erroneous conclusions from this association.

I find it difficult to find a suitable ward or room for the terminally ill adolescent. The adolescent is in the middle zone between the child and the adult. She/he does not belong with children any more, neither does she/he feel comfortable with adults. I visited a fourteen year old adolescent who was terminally ill, in a four bed ward, with three elderly men. Two of them were comatose, struggling with the final phase of their lives, gasping for air and surrounded by a grieving family. He looked at me and with real fear in his big brown eyes said: "Chaplain, is dying like that?"

#### 6.2.2 The Trauma of Isolation

As soon as the physician gives the news of a diagnosis of terminal illness, a child immediately "knows" he has something serious. His entire environment changes. The child quickly notices that the people whom he had previously trusted and loved are now keeping something frightening from him. Their silence is as if they were saying "Please don't ask me about this, for it is too terrible."<sup>41</sup>

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<sup>41</sup>Kliman, Psychological Emergencies of Childhood, p. 28.

Adamek<sup>42</sup> reports that staff in the hospital virtually avoid and isolate the terminally ill child.

It is interesting to note that in three separate visits to a terminally ill child, a total of eleven people entered the room under one pretext or another. The longest period spent in the room was approximately 30 minutes by a nurse's aide who gave morning care. The others remained from under one minute to approximately 5 minutes. Facial expressions were either sympathetic or matter of fact. The striking feature of all the activity in the room was the neglect of Mrs. B. (the mother)

LeShan<sup>43</sup> found in a research project done in a large New York hospital, that nurses consistently hurried to the rooms of the patients who were less near death, and as consistently dragged their feet in response to the summons of those who were at death's door. He concludes that their behavior had evidently been an unconscious expression of their aversion to death which had interfered with their care of their patients.

The terminally ill child in the hospital situation continually searches for verbal as well as nonverbal clues that can help him cope with his isolation. The child will listen to footsteps, tone of voice, and visually follow visitors around the room. Children detect subtle changes, a mother's tearful expression or the snapping together of a purse before a visitor enters the room.

Isolation is not only caused by physical desertion, by the fact that the terminally ill child is being pushed into a separate

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<sup>42</sup>Mary Elaine Adamek, "Some Observations on Death and a Family," Nursing Science (August 1965), p. 264.

<sup>43</sup>Margaretta K. Bowers et al., Counseling the Dying (New York: Nelson, 1964), p. 7.

room with drawn curtains, but also psychological desertion, by the inability of the staff and family to communicate in an honest and truthful way with the child when she/he starts questioning his/her illness and the possibility of his/her death.

Uncertainty about what is happening is the biggest problem of the terminally ill child. The child needs to know something about what is going on around him/her and where she/he is in time.<sup>44</sup> She/he needs to be prepared for what is going to happen to him/her; whether she/he is going for surgery or for tests, etc. Lying is always a mistake. When it is discovered by the patient she/he is left confused, angry, insecure and alone.<sup>45</sup>

When seven-year-old Peggy, who was dying, became suspicious and concerned about other children who 'disappeared' from the hospital ward, she tried a 'frontal attack.' She asked everyone she saw 'What is going to happen to me when I die?' Her physician answered: 'I hear my page.' Her nurse answered, 'You're a bad girl, don't talk like that. Just take your medicine and you'll get well.' But the minister replied with a question of his own, 'What do you think is going to happen?' The girl answered, 'One of these days I will fall asleep and when I wake up I will be with Jesus and my little sister.' 'That must be very beautiful,' said the minister, and at last the girl was satisfied.<sup>46</sup>

Physicians and parents often discourage any discussion of dying by comments such as, "Now don't you talk like that . . . everything is going to be fine." Such comments obviously communicate to the child that the topic is a forbidden one. Left alone with these

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<sup>44</sup>Adamek, "Some Observations on Death and a Family," p. 263.

<sup>45</sup>Renshaw, "The Dying Child," p. 23.

<sup>46</sup>David Hendin, Death as a Fact of Life (New York: Warner, 1974), p. 136.



questions one's answers must come entirely from one's own observations and fantasies. As it becomes increasingly difficult to construct a consistent story, the child may begin to lose trust in his/her parents. Parent-child as well as physician-child communication may break down, leaving the child isolated at the time when she/he most needs close interpersonal contacts. Every effort should be made to maintain open communication between physician and child, between parent and child and between the rest of the team and the child.<sup>47</sup>

If the child is helped to feel secure in spite of what is going on around him/her; if she/he is given adequate time and personal attention; if one is willing to play or read with a child; then the child will come to trust and accept such a person, whether it is a parent, or a doctor or a pastor or a nurse. I believe that trust is a cornerstone in open communication.

Kliman<sup>48</sup> reports on a study by Vernick and Karon who concluded their study of leukemic children in a hospital by asking the children: "Who's afraid of death in a leukemic ward?" They answered, "Everyone!" The resolution of that fear was everyone's problem on the ward. In an atmosphere of concrete freedom for their child patients to express their concerns Vernick and Karon found that most of the children already knew their illness and some knew exactly what was wrong. The staff was able to abandon traditional tactics of protecting

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<sup>47</sup>Stanford B. Friedman, "Management of Fatal Illness in Children," in Green (ed.) Ambulatory Pediatrics, p. 754.

<sup>48</sup>Kliman, Psychological Emergencies of Childhood, p. 42.

children by being secretive, and as a consequence became actively and constructively involved in helping their patients cope with the realistic experience of fear. They reported marked diminution in withdrawal, depression and behavior disorder which are so frequent on leukemia wards.

A child's concept of death varies with his age;<sup>49</sup> so too, does his anxiety about his illness. Whether he grieves and how he grieves about his dying is also related to his maturation and point of development.<sup>50</sup> Whether a child should be told of approaching death depends on the coping devices of each parent, on the family's desire and beliefs in this respect and on the child's ability to comprehend the idea and to integrate and cope with it. It must be stressed that each case is different and there are no pat answers.

But most important perhaps, is to be honest with the child. If the helping profession and the parents regard the child as a person with unique feelings and his/her own rights and are willing and able to listen to the terminally ill child; willing to allow the child to talk about what he/she knows and to ask the questions which are important to him/her, then there may be no need to ask whether the child should be told about his/her impending death or not! The child may do the telling!

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<sup>49</sup>See Chapter 6.1.

<sup>50</sup>C.M. Binger et al. "Childhood Leukemia; Emotional Impact on Patient and Family," New England Journal of Medicine, CCLXXX (February 1969), 414.

There is some evidence that children and their families are generally able to deal better with the reality of terminal illness than with socially enforced avoidance of that reality.<sup>51</sup> Families reported that they had a more meaningful relationship than ever before with their children because of openness in communication.<sup>52</sup> The child who can live through the process of dying in an atmosphere of sincerity and honesty, in the care and understanding of a dedicated and mature team and a loving family will come to appreciate the fullest meaning of life itself.<sup>53</sup>

#### 6.2.3 The Psychology and Needs of the Terminally Ill Child

For simplicity's sake I shall divide childhood into three phases:

- (1) from birth to five years: infant, toddler and preschool child
- (2) from six to ten: grade school child
- (3) from ten through adolescence.

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<sup>51</sup>Gilbert Kliman, "The Child Faces His Own Death," in Austin H. Kutscher (ed.) Death and Bereavement (Springfield, IL: Thomas, 1974), p. 20.

<sup>52</sup>Sarah Sheets Cook, "Childrens' Perceptions of Death," in her Children and Dying, p. 10.

<sup>53</sup>Yvonne Craig, "The Care of our Dying Child," in Lindy Burton (ed.) Care of the Child Facing Death (London: Routledge and Kegan Paul, 1974), p. 87.

I realize that this grouping is arbitrary since this grouping is neither fixed or precise.

#### 6.2.3.1 The Infant, Toddler and Preschool Child

The younger the child the more his/her affective responses to dying will be influenced by those around him/her. The exceptions, of course, are infants under six months of age. They do not yet recognize the environment as separate from themselves and therefore suffer only the physical ravages of the terminal process.<sup>54</sup> Growth brings every child the opportunity both for life and for death. The whole body strives to maintain life as long as possible in the face of the death agony.

The preschool child can face his/her own dying only with the primitive understanding and the limited emotional strength of the very young. The infant and toddler are dependent upon parents and those around them for their very existence—for food, for guidance and for basic day-to-day decision making. She/he does not understand death. She/he has not learned how to react to dying. She/he takes his cues from his/her parents, his/her family and from the treating personnel about how she/he should respond to the disease process. His/her personal dying only has meaning to the toddler as it affects the people around him/her.

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<sup>54</sup>Easson, The Dying Child, pp. 21-22.

The hospitalized toddler reacts strongly to the fact of his/her not being at home. With his/her searching eyes, his/her awkward hands and his/her whole groping body, she/he struggles for that one person—mother. Mother means safety and guidance. She/he does not understand or trust the other people around him/her. She/he does not know what to do. As his/her tension and anxiety mount she/he cries until final exhaustion. To add to the emotional burden of the toddler the strange people "in white" cause him/her pain. They stick needles into his/her body. They probe him/her with tubes. They handle him/her roughly. They do not have time to feed him/her when he is hungry or change him/her when she/he has soiled. They do not understand what she/he's trying to tell them.<sup>55</sup>

The toddler feels the pain of separation from parents as acutely as that associated with his/her disease process. The child's wailing or despairing silence, anorexia or restlessness may subside if a parent is always present, and if appropriate psychopharmacologic measures are administered.<sup>56</sup> The toddler starts to assert his/her individual opinion and thus to emphasize his/her differences, his/her uniqueness and his/her separateness. While she/he is achieving this definite understanding that she/he is a "me," she/he is, at the very same time, beginning to appreciate that somehow there can also be a

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<sup>55</sup>Ibid., p. 22.

<sup>56</sup>Penelope R. Buschman et al., "Use of Psychopharmacologic Agents in the Care of the Terminally Ill Child: A Nursing Overview," in Ivan K. Goldberg (ed.) Psychopharmacologic Agents For the Terminally Ill and Bereaved (New York: Columbia University Press, 1973), p. 287.

"not me." This awareness of a possible "not me" is extremely disturbing, not only to the young child, but to every person from that age onward. The child handles the primitive anxiety aroused by this fear of not being in a fashion appropriate to his/her maturation level. She/he has no option but to suppress these ideas of "not me" because the feelings aroused by these concepts would cause such intense personal anxiety that she/he could not continue to function if she/he allowed him/herself to feel these emotions.

Generally, the child is four, five or six years of age before she/he has a definite stable concept of him/herself. It is at about this age that the child obviously begins to deal with his feelings about being and not being. Normally and naturally, those disturbing feelings are covered over and blocked away by denial and repression. Sometimes the preschool child cannot totally repress these emotions. This is the age when nightmares are most commonly seen in normal children. The child who weakens physically as the disease advances, finds him/herself weaker emotionally and thus less able to deny the mounting threat to his/her being. The restlessness of the dying child may be an outward indication that she/he is becoming less and less able to contain and control his/her anxieties as death grows nigh—and is thus a sign that his/her strength is failing.<sup>57</sup>

She/he may experience physical limitations and distress, internalizes certain fears and becomes quite angry at being "the child

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<sup>57</sup>Easson, The Dying Child, pp. 9-12.

at the windows." She/he may resent bitterly the fact that she/he can no longer do what she/he wants to do in the way that she/he likes. This may evoke his/her anger. She/he may whine, become highly dependent or fiercely independent acting as though he has no handicap. His/her behavior may fluctuate with the degree of his/her illness. At points of severe distress, she/he may vary from marked withdrawal, full panic, or endless demands on his/her parents.<sup>58</sup>

Anxiety in the terminally ill child may show regression to earlier behavior, such as bedwetting, thumbsucking, rocking, temper tantrums and fluffy toy clinging.<sup>59</sup>

The young child has no concept of change. She/he cannot grasp the fact that some things can happen naturally and spontaneously. She/he believes sincerely that everything happens because someone is doing something to someone else. Thus when the toddler is hospitalized with terminal illness she/he is liable to consider that this separation from his/her home and his/her family is a punishment.<sup>60</sup> His experience of pain is complicated further by the notion that such a penalty (illness) only occurs because of badness and that perhaps she/he is responsible for the mishap that has befallen him/her. She/he may react in childish guilt, sadness and withdrawal.

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<sup>58</sup>Giulio J. Barbero, "The Child, Parent and Doctor in Death From Chronic Disease," Journal of Thanatology, 1:4 (1971), 285.

<sup>59</sup>Renshaw, "The Dying Child," p. 22.

<sup>60</sup>Easson, The Dying Child, p. 26.

Pain is marked by regressive behavior, despair, agitation, irritability and disinterest in diversionary activity.<sup>61</sup> Anxiety, fear and depression frequently appear to enhance the subjective experience of pain.<sup>62</sup>

A minority of preschool patients become increasingly rebellious and antagonistic in the hospital. This reaction stems from the child's denial of guilt and his/her projection onto and subsequent anger toward his/her parents or staff for either causing or allowing this tragedy to happen.<sup>63</sup>

The pediatrician often perceives the demands of the dying child and his/her family as overwhelming. She/he does not know how to mitigate their grief and she/he has already done everything that she/he knows how to do to save the child. She/he may be angry about his/her own helplessness and this anger is sometimes directed towards the child and the family who she/he feels, are expecting more of him/her than should be expected of any human being. Robinson<sup>64</sup> quoted as an example of the reaction of a capable conscientious pediatric resident who literally worked day and night to keep the child alive but the child's condition deteriorated rapidly. Finally

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<sup>61</sup>Buschman, "Use of Psychopharmacological Agents . . . ," P. 288

<sup>62</sup>John E. Schowalter, "Drugs, Fatally Ill Children, and the Pediatric Staff," in Goldberg, Psychopharmacologic Agents for the Terminally Ill, p. 297.

<sup>63</sup>John D. Schowalter, "The Child's Reaction . . . ," p. 57.

<sup>64</sup>Mary E. Robinson, "The Pediatrician and the Dying Child" in Cook, Children and Dying, pp. 47-48.



exhausted and outraged he said to a supervisor: "I get so mad at that kid, sometimes I could slap her across the face. How dare she die in spite of everything I've done!"

Paramount in the needs of the terminally ill child is the presence of a loved one.<sup>65</sup> It is important that avenues of communication are being kept open. The dying child needs to express his feelings and his fears; verbally if he is capable or through play media if she/he is not. Eissler suggests that one of the chief needs of the dying child is love and that the chief manifestations of love are a readiness to help, anticipation of needs, the providing of trust, courage and consolation.<sup>66</sup> Efforts to "cheer-up" a youngster may be ineffective and inappropriate—if there is obvious suffering. Honesty is crucial! Parents must be encouraged to be honest with their child when explaining the reasons why he/she is in the hospital. Most children will accept the idea of hospitalization without too much difficulty if they are convinced that the parents believe that this is best and there is no alternative.<sup>67</sup> Often parents have more problems here than the child. The best way to help the child in such a situation is to help the parents.

For many children the fear of pain, bodily harm and the anguish of loneliness and unfamiliarity are the worst hazards of being

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<sup>65</sup> Adamek, "Some Observations on Death and a Family," p. 263.

<sup>66</sup> Ibid., p. 266.

<sup>67</sup> Potter, "Specific Problems . . . ," p. 53.

in a hospital. They should be given frequent reassurance. The secret is to give the child a sense of security which means sharing with and trusting in someone else.<sup>68</sup>

Since the preschool child has no clear concept of time, he may feel the separation of death to be merely an overnight sleep, with the assurance of parental love on the awakening. With this support and understanding, the pre-school child can die, secure in the firm knowledge that Mommy and Daddy will never leave him. They will always be with him. With this understanding that his parents accept him, good as he is and naughty as he may sometimes be, the young child can pass through these final stages of life and tolerate the discomfort of death. He can sleep in peace.<sup>69</sup>

#### 6.2.3.2 The Grade School Child

Most children above four years of age, although not told directly of the diagnosis, presented evidence to their parents that they were aware of the seriousness of their disease and even anticipated their premature death. The children who were perhaps the loneliest of all were those who were aware of their diagnosis but at the same time recognized that their parents did not wish them to know.<sup>70</sup> Older children often feel that if the parents cannot talk

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<sup>68</sup>Richard Lamerton, Care of the Dying (London: Priory Press, 1973), p. 66.

<sup>69</sup>Easson, The Dying Child, pp. 36-37.

<sup>70</sup>Binger, "Childhood Leukemia . . . ," p. 415.

about what's happening they must protect their parents and respect this "silence." Parents usually have someone to talk to, but the terminally ill child may have to deal alone with his/her fears, concerns and apprehensions and also cope with his/her own inner scheme of fantasies and "white lies" developed by the parents so that meaningful communication between parents and child is prevented.<sup>71</sup> Unless a child of this age repeatedly and specifically asks whether or not she/he will die, it is usually better not to tell him/her. It is easier for him to deny his own judgment than that of the doctor, pastor or parents, and she/he should be allowed to use this defense if she/he wishes.<sup>72</sup>

The child's feelings about him/herself and his/her condition are important in determining his/her level of discomfort as well as his/her manner of communicating this discomfort to the staff. Most children have an elaborate fantasy life. Many children may view their illness and its treatment as a punishment for wrongdoing. These patients may underact, accepting pain as justified and perhaps anticipating a cure as the forgiveness and reward for their silent suffering. Often these fantasies are far more harmful than the plain facts. The essential needs of any sick child are to have reassurance that she/he did not cause his own illness and that it is

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<sup>71</sup>Ibid., p. 417.

<sup>72</sup>Schowalter, "The Child's Reaction . . . ," p. 61

not a punishment for anything she/he did or failed to do.<sup>73</sup>

School age children may guard the area where their pain is most exquisite and prefer to remain in bed in one position. They may withdraw from surroundings and adults caring for them. They may articulate their pain in words, body position and facial expression. Their behavior may be regressive and if pain is prolonged without relief they may cry and moan. Some children will not complain verbally of their pain and will deny its presence if asked. For them the threat of an injection, a difficult procedure or a longer hospitalization is greater than that of enduring the pain.<sup>74</sup>

Most grade school children are scared, lonely and sad when they are first sent to the hospital. They feel lonely away from their parents and siblings. They miss them. They may become angry, frustrated and anxious because they are away from home. After some time they are usually able to manage and to cope.

Rapidly they become sensitive to the anxieties on the unit. They discover that extra visiting privileges mean that death is fast approaching. They discover that patients as they approach death somehow tend to be moved nearer the door. They notice that the treating staff seem to pass more hurriedly by the patients who are failing physically. The doctor even has a special face and manner of

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<sup>73</sup>Lindy Burton, "Cancer Children," New Society (June 17, 1971).

<sup>74</sup>Buschman, "The Use of Psychopharmacological Agents . . . ," p. 288.

greeting when the case is doing badly. Though they quickly learn the fears and anxieties of their hospital unit, they also become part of the total group denial process that exists on such a unit. With the support of those around him, she/he will find that she/he does not really notice when bed patterns change. She/he will be taught not to become outwardly disturbed when a member of the patient group disappears and never returns. Each patient works with the other patients to support this denial and to maintain the necessary facade. Unfortunately this kind of group denial sometimes gives way under the pressure of group anxieties. A whole hospital ward can become deeply and disturbingly anxious and upset. They are learning that death will not go away and that death happens even to the young.<sup>75</sup>

Studies indicate that anxiety about death and dying was found chiefly among the older children. However, there were indications that anxiety about death may have been present in more subtle form in younger children, even though overshadowed by fear of separation, or fear of the procedures. Such indications were sometimes found in the drawings and stories of children. The death of another child in the hospital occasionally was identified as the source of manifest death anxiety.<sup>76</sup>

As part of the normal emotional and intellectual growth process, the grade school child begins to fantasize an alternative to

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<sup>75</sup> Easson, The Dying Child, pp. 45-47.

<sup>76</sup> Robert Kastenbaum and Ruth Aisenberg, The Psychology of Death (New York: Springer, 1972), p. 77.

death—a hereafter, a heaven, a paradise or even a hell. In this way she/he reassures himself that his newly developed individuality that she/he now appreciates and enjoys will continue to exist. Even if this present individuality is changed in some way, possibly by a process called death, there will still continue to be a "me," there will still be a post-self! Even a continued existence in the torments of hell may be preferable to the horrible, formless anxiety of not existing at all. The child wants his existence to continue. Heaven of course, is by far the best solution.<sup>77</sup>

Schowalter feels that children exposed to death in a non-frightening way tend to be more open and less fearful about death than those without exposure. A child who believes in a benevolent God and a reunion after death with loved ones may appear less fearful than a child without hope. Religion per se, however, is no certain safeguard against the fear of death. On the contrary, some of the most terrified and inconsolable children are the product of juxtaposition of earthly guilt with the belief in a malevolent God.<sup>78</sup>

The growing youngster, age six to ten, cannot avoid being aware of what is happening to him/herself. She/he can, however, share his/her burden in a respected and trusting relationship. His/her expressed fears must be answered honestly and care must be taken not

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<sup>77</sup>Easson, The Dying Child, p. 43.

<sup>78</sup>Schowalter, "The Child's Reaction . . . ," p. 60.

to incite anxiety in other areas. She/he should be given a reason and explanation of every procedure and she/he should be prepared in advance for major ones—like surgery.

If his/her parents are open and supportive she/he will turn to them for security and for comfort and she/he and his/her parents can share their deep bond of love and understanding. The experience of death can be the deepest and warmest relationship that the grade school child will ever have had with his family.

Yea, though I walk through the valley of  
the shadow of death, I will fear no evil:  
For Thou art with me; Thy rod and Thy  
staff they comfort me.<sup>79</sup>

This Psalm of trust and belief in God could have been said by a grade school child. A grade school child believes in parents and in God. She/he knows that death means a final separation from this life. She/he knows now what she/he will miss. She/he must mourn this loss as she/he leaves. She/he is sad and bitter because she/he does not want to go. She/he is lonely because she/he is traveling this journey alone. In this very difficult time, the grade school child can use his/her parents, his/her family, his/her friends, the hospital staff to help him/her live through this final experience. The grade school child always uses the support of those whom she/he trusts. In his/her final days and hours, she/he should pass through death in the comfort and security of his/her family.<sup>80</sup>

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<sup>79</sup> Psalm 23.

<sup>80</sup> Easson, The Dying Child, pp. 48-49.

#### 6.2.3.3 The Adolescent

While the young adolescent is deliberately emancipating from his family and his/her parents this emotional growth and separation is not without pain or guilt to the teenager him/herself. Because she/he is now rejecting parental control, the young adolescent feels vaguely bad and uneasily guilty. When she/he is stricken by a terminal illness she/he sees it as a punishment for a multiplicity of sins she/he has committed.<sup>81</sup>

The rapidly changing adolescent, confronted with the physiological revolution within him/herself and with the varied intellectual, social and vocational demands of adulthood that lie directly ahead, is concerned with how she/he appears in the eyes of others, compared with how she/he feels she/he actually is, and with the question of how to connect the roles and skills cultivated earlier with the demands of tomorrow. The adolescent's body becomes very important and she/he may spend much time in front of a mirror viewing him/herself. The sense of body image in the adolescent is closely related to the development of a clear sense of ego identity. Other important factors in the development of the adolescent's identity are: the kinds of parent-child relationships she/he has had and the previous identifications she/he has developed; his/her ability to integrate these identifications with his/her new-found sexual maturity; the

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<sup>81</sup>Ibid., p. 53.



aptitudes and skills she/he has developed out of his/her ability and experience; and the opportunities offered in social roles.<sup>82</sup>

Just at the time when secondary sexual characteristics, independence, self-identity, and a lust for life begin to develop, the terminally ill adolescent is faced with bodily deterioration, forced dependency, disintegration of the self and death.<sup>83</sup> The adolescent separated him/herself from his family and invested his/her time and energy in his peer-group; in the gang! Now she/he finds his peer-group is uncomfortable in his/her presence, with his/her illness and that they withdraw from him/her. She/he experiences increased isolation and loneliness and becomes discouraged and fearful. So newly emancipated, she/he resents the curtailment of his/her freedom. Everything that is happening to him/her, everything she/he experiences engenders intense anger and guilt and it may produce a total denial of what is happening.

The effect of the disease on the patient's self-image may be variable according to the severity of the disease, his age, his introspectiveness and the way the problem is presented to him by his parents, siblings, relatives, friends and medical personnel.<sup>84</sup>

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<sup>82</sup>Paul Mussen, et al., Child Development and Personality (New York: Harper & Row, 1969), p. 690.

<sup>83</sup>Schowalter, "The Child's Reaction . . . ," p. 64.

<sup>84</sup>Lucas Kulczycki, "The Impact of Cystic Fibrosis on the Parents and Patients," Journal of Thanatology, I:5 (1971), 330.

It is important to recognize that behavior patterns of adolescents will be somewhat similar to those of adults. Now he has an almost adult capacity to understand death and to respond to the threat of terminal illness.

Despite the ability of the adolescent to talk about the site, duration and nature of the pain she/he experiences, most often it is impossible for him/her or the staff to distinguish between physiological and psychic pain. The two are intermingled, each compounding the other. Rather than a specific complaint, the pain may be located "all over." A frequent reaction among adolescents involves the previously stoic teenager who finds anxiety and depression and pain unacceptable to his/her self-image, but now experiences them nevertheless. The anxiety and depression only heighten his/her responses to the pain (crying out, complaining, asking for medication, etc.) and these responses in turn increase his/her anxiety and depression.<sup>85</sup>

The reaction of the terminally ill adolescent consists largely of anxiety. In fact, they seemed to constitute, in turn, fear of separation, fear of mutilation and fear of death. Observation suggests that fear of death is related to other fears in the maturational pattern.<sup>86</sup> To become aware that one is going to die triggers what Solvet and Green have perceptively noted, one of a

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<sup>85</sup> Buschman, "The Use of Psychopharmacologic Agents . . . ," p. 298.

<sup>86</sup> Kastenbaum and Aisenberg, The Psychology of Death, p. 77.

person's deepest fears—death before fulfillment.<sup>87</sup>

It is important to respect the individual as a person, despite his illness; to consult with him and to explain the procedures of what is being done and the reasons for it. A fourteen year old said in relation to a liver biopsy: "They called my mother to get permission. I know it is necessary, but I'm mad. My doctor didn't talk to me about it—it's my liver!"<sup>88</sup>

It is important to give the terminally ill adolescent the reassurance of continuing medical care; to let him/her know that someone knowledgeable is available at all times to help cope with an emergency or to answer important questions.

As death grows nearer the disease process may deform before it destroys. A slow death may cause the dying adolescent a great deal of emotional agony. The active masculine, young man, so proud of his body, may be maimed and disfigured before dying takes its toll. Before the metastases finally lead to her death, the 16 year old girl may have to undergo a deforming amputation as the cancer spreads. Because the fourteen-, fifteen- or sixteen-year-old adolescent has tasted the pleasures of personal mastery and self-achievement, she/he feels death to be a greater deprivation. She/he is enraged. She/he is furious. There is never any justification sufficient for this kind of personal insult! The competent adolescent hates death!

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<sup>87</sup>Schowalter, "The Child's Reaction . . . ," p. 62.

<sup>88</sup>Cook, "Children's Perception of Death," p. 11.

The adolescent is finding that as she/he cares for other people she/he is growing emotionally and spiritually; when death comes to him/her, she/he knows he/she can no longer grow. As death approaches, the older adolescent, the young adult, may draw closer emotionally to the members of his/her family. She/he can allow her/himself to be cared for and she/he can continue to care. The adolescent who is dying should be dealt with on the basis of truth and respect, no matter what age she/he may be. As with any other patient, of any age level, the adolescent will indicate by his/her questions what kind of answers she/he wishes. If she/he needs to deny the reality she/he should be allowed this emotional defense. Perhaps what is necessary is sensitive people, willing to respond with empathy to him/her where she/he is, in an atmosphere of quiet warm security.

The more mature teenager, the young man or the young woman, can usually allow family members to comfort and to care. Sad, but proud, the older adolescent can go to his/her death mourned and mourning. The younger adolescent, age ten to fifteen years, may be much too proud and bitter to accept any form of comfort. Defiant of death, desperately proud and painfully lonely, the younger adolescent may go to his/her death fiercely independent to the end.<sup>89</sup>

### 6.3 Pastoral Care of the Terminally Ill Child

In my contact with hospital chaplains and ministers and in my working with students in Clinical Pastoral Education programs I found

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<sup>89</sup>Easson, The Dying Child, pp. 59-65.

that the vast majority do not visit children's wards at all. Those who do visit feel uncomfortable and "out of place." They tend to rush smilingly through the ward. I concluded that terminally ill children are subject to gross negligence in terms of pastoral care.

Some of the reasons given were:

- (1) "I find the pastoral care of a terminally ill child very difficult and emotionally draining. I avoid the terminally ill child consciously."
- (2) "I feel my studies and training were inadequate to help me understand and deal with a terminally ill child."
- (3) "I cannot communicate with children. I do not understand them and they do not understand me."
- (4) "It's too time-consuming. There are other more important things to do."
- (5) "A child does not understand anything about dying. I prefer to give my time and support to the parents who are really suffering."
- (6) "I am only a few years older than J. (a terminally ill adolescent.) His dying brings death close to me. I identify too much with him."
- (7) "The terminally ill child reminds me of my own children. At this point I'm just not willing to work through and accept the possibility of losing my own children."

Pastors are certainly not a separate group in their response to the terminally ill child. Their feelings about terminally ill children are typical of the majority of adults in our society. Of all

dying patients, children usually create the greatest emotional strain for the hospital staff. The death of a child strikes all as an exceptional and tragic waste. The inability to prevent a child's death fosters feelings of impotence and failure.<sup>90</sup> Staff members work best with dying children when they feel some, but not overwhelming emotional discomfort with the patient. If the child's agony is too obvious, the staff abandons him/her, and if the child is too heavily sedated, the staff ignores him/her.<sup>91</sup>

The pastor's care of the terminally ill child will be most frustrating and unsatisfactory if she/he is not an accepted and respected member of the team. In order to minister adequately to the needs of the terminally ill child she/he needs to sit in on case conferences; to accompany the team on their daily rounds on the ward and have access to the patient's chart.

I am aware of the fact that this does not seem realistic for the parish pastor. In Chapter Eight I will deal more specifically with the parish minister and how he can minister more adequately to terminally ill patients.

The pastor is a member of the team but there is one important thing that distinguishes him from the other members of the team that makes it easier for him to deal with and accept the terminally ill patient. All those who have chosen the provision of health care

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<sup>90</sup>Schowalter, "Drugs, Fatally Ill Children . . . ," p. 296.

<sup>91</sup>Ibid., p. 302.

services to the sick as their vocation—be they physicians, nurses, practical nurses, nurse's aides, occupational, physical or recreational therapists, psychiatrists or medical social workers—have in common the desire to help sick people get well. When sick people fail to get well a number of not-so-obvious reactions may supervene in any or all of the aforementioned health care workers. A patient's failure to get well frustrates one of the primary goals and needs of the health care worker, and feelings of frustration lead rapidly to feeling angry. But how can one be angry at a sick—still worse, at a dying—child? And thus arises the feeling of guilt. Guilt, being an unpleasant feeling, in itself produces a reaction of anger at the one who caused the guilt feeling, and self-sustaining emotional chain reaction has begun. This chain reaction may occur on a conscious, partly conscious, or totally unconscious level, and its intensity in a given situation will determine the degree to which it interferes with the provision of patient care.<sup>92</sup> The pastor is the only member of the team for whom the patient need not perform by responding to the treatment. This frees the pastor to enter into a different and special relationship with the patient. She/he is free to accept the patient, even though she/he is losing his/her grip on life and dying. She/he is free to accept the terminally ill child as a precious human being in spite of a deteriorating and misformed body. The pastor,

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<sup>92</sup>Michael B. Rothenberg, "Problems Posed For Staff Who Care For the Child," in Burton, Care of the Child Facing Death, pp. 39-40.

as a member of the team has a unique opportunity and major responsibility in his/her caring of the terminally ill child.

Our society and practices in our society are changing rapidly and create new responsibilities and challenges for the Church and the minister. For many years the doctor went on house-visitation. He visited the sick at home and became a respected and loved "member" of the family. He was available to support and to give advice in times of illness and death. The medical doctor in our modern society has become a cold impersonal technician with no time for a personal conversation. He is no longer the family friend and confidant. His place is empty and could easily be filled by the sensitive loving minister, once again willing to visit families in their homes!

The pastor has to recognize his/her own human feelings, his/her own fears and his/her own attitudes toward death. Only then will she/he be comfortable in spending time in the room of the terminally ill child without a specific manual task to perform; without using the Scripture and prayer to hide his uncomfortableness.

Cicely Saunders writes: "We will never help the anxieties of others if we do not try to understand and handle our own. A first step is to discuss them with others concerned. A high degree of emotional stress may remain hidden and need resolution."<sup>93</sup> This stresses the importance of a support group for the pastor who works with the

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<sup>93</sup> Cicely Saunders, "The Management of Fatal Illness in Childhood," Proceedings of the Royal Society of Medicine, LXII:6 (1969)



terminally ill. She/he will have such a support group if involved in Clinical Pastoral Education. If not, she/he may wish to form his/her own group, consisting of other ministers in the area and/or members of the team. This group can consist of 4-8 members, meeting once a week.

An important aspect of establishing communication with the terminally ill child seems to be obstacles to empathy; the capacity of a person to feel instinctively and intuitively as another does. The ability of the pastor to understand the terminally ill child will depend on his/her being able to get in touch and experience his inner child.

Important is how the pastor feels about children and youth. This is determined largely by the pastor's relationship with one particular child or teenager—the one inside him/herself. If the pastor's inner child is a stranger he/she will distort the pastor's relationship with children and young people. She/he will cause the pastor to fear them or "preach at" them.

It is necessary to reconnect with one's inner child or adolescent. One method of accomplishing this is to use the following fantasy:

Close your eyes and imagine a movie screen in your mind. Flash on it the house you lived in as a child. Now picture yourself coming home from school. See yourself as you looked then. How do you feel? Picture some incident with your parents . . . with your closest friend . . . alone (feeling what you felt, in each case). Picture the most painful experience you can recall from those years. Feel it . . . Make friends with the child in your mind . . . Chat with him/her . . . Tell him/her how you feel relating to him/her . . . If she/he still hurting, comfort him/her. You need each other very much.

Another possibility is to draw a picture of yourself as a child and reflect on it for a few minutes. Following this, use the fantasy exercise to picture in your imagination some experience of your childhood, attempting to relive the original feelings. If possible share it with someone you trust or with a support group. Ineffectiveness in ministering to a child or an adult is often rooted in unresolved guilt, dependency, and resentment toward one's own parents, living or dead.<sup>94</sup> Inherent in obstacles to empathy with the terminally ill child is the pastor's own fear. However, if the pastor is able to recognize and verbalize his/her feelings she/he would be able to enter the world of the terminally ill child, understand his/her anticipated loss and accept his/her feelings. If we do not share, or help others to share in the patient's experience, we deny the patient the means of finding a way through it.<sup>95</sup>

Communicating with children about their illness and impending death requires skill gained through thoughtfulness and experience. It is rarely necessary to give detailed explanations to young children. The important point to communicate is that one is willing to talk and to listen and most importantly, that the child can trust the pastor. If the pastor does not have an answer—she/he never lies—but rather admits that she/he does not know the answer. There is a

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<sup>94</sup>Howard J. Clinebell, Jr., The People Dynamic (New York: Harper & Row, 1972), pp. 92-93; 102-103.

<sup>95</sup>Saunders, "The Management of Fatal Illness . . . ."

great deal of nonverbal communication between the child and the adult, and children form opinions from the way adults act.

The building of trust and rapport are paramount in our efforts to help the terminally ill child through a very difficult time.

How does one establish contact with a child? I feel that a pastor must be willing to use body language and other non-verbal techniques to establish rapport. One must assess very quickly how withdrawn a child is. This can be done by using fingerplay and making a game of walking towards a child with one's fingers. By the child's reaction, one can determine whether or not physical touch is possible. Being able to touch a child and being comfortable about it yourself and having the child comfortable is very important.

Often times a child is so withdrawn that one will have to use other media rather than voice and touch to establish rapport. It is most helpful to have a hand puppet with you to talk with children. Often times one can talk on the telephone or have your doll talk with their doll and get the most intimate information. Try to get the older child to draw a picture. This is most revealing. With a little imagination and enthusiasm the pastor will find many avenues opening up for him.<sup>96</sup> Only by having or making time for leisurely conversation, often when the child plays, will it be possible to answer his real questions and allay his/her fears. The pastor must be

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<sup>96</sup> John Schaefer, "Establishing Rapport with Hospitalized Children," Bulletin of American Protestant Hospital Association (1972) 87-89.

sensitive to the problems that are important to the patient although they may seem rather peripheral to him/her.<sup>97</sup>

Another communication tool that can be used by the pastor is the Mutual Storytelling Technique.<sup>98</sup> Mutual Storytelling invites the child to tell a completely imaginary story to another person (pastor). Once the child has related his/her story, another version of the story is told in return by the second individual (the pastor). This second story aims at reinterpreting the original, seeking to present different alternatives for the outcome or different character models for the main actors.

Stories are made up of characters, events and morals (lessons) in this technique; thus the reinterpretation focuses on one or all of these items. For example, a moral in an original story told by a child once lamented: "You can't trust anyone you don't know." The second moral gave this encouragement: "When people care for you they can be trusted."<sup>99</sup>

The child is a person and has his/her own worth. The pastor must know his/her name. Access to the patient's chart will provide valuable information about the parents and the siblings. Personalized care based on an intimate knowledge of the child and a sensitivity

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<sup>97</sup>Toch, "Too Young to Die," pp. 67-68.

<sup>98</sup>Richard A. Gardner, Therapeutic Communication with Children (New York: Science House, 1971).

<sup>99</sup>Christopher C. Schooley, "Communicating with Hospitalized Children: The Mutual Storytelling Technique," The Journal of Pastoral Care, XXVIII:2 (1972), 102f.

and responsiveness to his/her needs, contributes greatly to the child's confidence and sense of worthiness. This attentiveness is demonstrated through the kind and thoughtful way in which the pastor talks to the child; remembrance of birthdays, Christmas and other important events in the family life; Spontaneous conversation about things of interest to him/her's alertness to his/her feelings of discomfort, depression and fear. "You seem kind of discouraged today."; the assurance that the illness is not his/her fault; understanding of his/her fearful reaction to new or painful procedures; patient attempts to understand why the child may be uncooperative; the avoidance of criticism, sermons, threats or exhortation, and an acceptance of negative feelings which she/he may express directly or indirectly.

The young child who is dying is handled and dealt with on the basis of here and now. She/he is given support in every way to help him/her cope with his/her present reality. His/her questions and problems are answered in terms of today.<sup>100</sup>

When a child is too young or frightened to ask, reassurance can be given in indirect fashion by telling stories about other children. One mother of a five year old, suffering from a brain tumor used to tell the story of a little prince who fell sick and developed a nasty pain in his head. She would say:

Whilst he was getting better, his mother stayed with him all the time and talked to him and kept him from feeling lonely. When his

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<sup>100</sup> Easson, The Dying Child, p. 33.

head hurt the doctor came and helped to make it better. The doctor and the prince's mother were always near him, keeping him safe and comfy and being sure he was never alone.<sup>101</sup>

Schowalter stresses the fact that children who ask whether they are dying do so less for a definite answer than for reassurance that they will be kept comfortable and will not be abandoned. Such reassurances should always be given.<sup>102</sup>

Human, warm attentiveness to the concrete and practical details of physical comfort is important. Children who experience great pain are fearful and need reassurance from the parents and members of the team. The simplest and the most significant of the humanistic measures contributing to the relief of pain in children is touch, the ancient rite of the "laying on of hands."<sup>103</sup> It will serve the pastor well to keep this in mind.

Christ is significantly associated with children and youth and employed an impressive "touching" ministry. A rather familiar text is Mark 10:13ff:

And they were bringing children to him that he might touch them; and the disciples rebuked them. But when Jesus saw it, he was indignant (a strong word), and said to them, Let the children come to me, do not hinder them; for to such belongs the Kingdom of God. Truly I say to you, whoever does not receive the Kingdom of God like a child shall not enter it. And he took them up in his arms and blessed them, laying his hands upon them. (RSV)

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<sup>101</sup>Burton, "Cancer Children."

<sup>102</sup>Schowalter, "Drugs, Fatally Ill Children . . . ," p. 299.

<sup>103</sup>Buschman, "Use of Psychopharmacologic Agents . . . ," p. 297.

To touch a child, and to bless in the touching has compelling beauty in this account.<sup>104</sup>

Pastors are often tempted to describe heaven as a beautiful place, with golden streets and birds and deer feeding out of one's hand, to the terminally ill child. Often this is done to cover feelings of helplessness. However, it is necessary to remember that most young children are not really happy to go to Heaven, because this journey means a separation from their parents and family. The youngster does not want to leave home, because she/he is happy with his/her mother, father and family. Are they sending him/her away because they do not want him/her? In answer the dying child can reasonably be told that his/her parents do not want him/her to go and that they will miss him very much indeed. He and his parents can feel sad together that they are going to be separated. They can understand and can comfort each other.<sup>105</sup>

If one is willing to look and to listen to the adolescent, most terminally ill adolescents react in such a way as to indicate that they know they are dying. Those adolescents who will talk about dying express less separation anxiety and fear of procedures than do younger children, but despair over not being fulfilled seems almost universal. Some adolescents find comfort in anticipating a religious fulfillment in heaven. Clinically, it would appear that there are

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<sup>104</sup> Robert Wedergren, "To Touch a Child," Bulletin of the American Protestant Hospital Association (1972), 85.

<sup>105</sup> Easson, The Dying Child, p. 36.

fewer religious fears of death during adolescence, than during the early school age or the period of latency when conscience and ideals are often so strict.<sup>106</sup>

The pastor can also run into a lonely, rebellious and angry adolescent. I visited a 15 year old and when I introduced myself he confronted me with: "Pastor I don't want to hear any of your God-talk!" I continued to visit him, stayed interested, loving and supportive. Eventually the action spoke louder than the words and he opened up in a very meaningful relationship.

If at all possible rapport must be established before the final phase when closeness and a touch is far more important than words. The terminally ill child must be visited frequently and when a promise is made to visit on a certain time it should be kept.

The pastor has a special responsibility towards the other members of the team involved in the care of the terminally ill child. Helping the staff to give appropriate comforting care to a dying patient is a long process that is never completely mastered. A factor seldom given enough emphasis is that staff members need support in order to give support. Often this support is derived from members feeling a sense of community in their work. But this is not enough. The pastor has to be sensitive to their needs and be a catalyst in a supportive way.<sup>107</sup>

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<sup>106</sup>Schowalter, "The Child's Reaction . . . ," p. 65.

<sup>107</sup>Schowalter, "Drugs, Fatally Ill Children . . . ," p. 302.



Where no play therapist is available, particularly in his ministry to the child in play age the pastor may find it desirable to acquire some skills in principles of play therapy.<sup>108,109</sup> The pastor may also initiate a therapy group for terminally ill children where they are free to express their concerns and feelings.

Pastoral care is directed to the terminally ill child as a member of a family and never as an individual, separate from a family. I will discuss the pastoral care of the family of the terminally ill child in 6.5.

#### 6.4 The Family: Parents and Siblings

As I entered Eric's room, I had the distinct feeling that he would die very soon as his breathing was very labored and Dr. Martinson had said she thought his breathing may get very erratic at the end. I sat by his bed and he held my hand. I asked if he needed anything and he said "no." An hour later, I thought he was finally resting more peacefully as the difficult breathing wasn't evident. I laid on the floor to get some rest but as I lay there, I listened for his breathing but couldn't hear it so got up to check. There was no more breathing or heartbeat; Eric had died while holding my hand, at peace at last.

For the last time, I held my son, told him how very much I had loved him and that 'Jesus will take care of you now.' I got Del and we returned to Eric's room. I gently wiped the side of his mouth which led Del to comment, 'Thank God, he no longer hurts when he's touched.' The dreaded fear, death, wasn't ugly like I had thought it would be—Eric was at peace. We, too, had a feeling of peace—Eric's problems were over and we did not have to bear the guilt of not having done all we could for our son, besides having to bear his loss, which was in itself more than great enough a burden . . . .<sup>110</sup>

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<sup>108</sup>Virginia M. Axline, Play Therapy (New York: Ballantine Books, 1974).

<sup>109</sup>Virginia M. Axline, Dibs, In Search of Self (New York: Ballantine Books, 1974).

<sup>110</sup>Ida Marie Martinson, Eric (Minneapolis: University of Minnesota School of Nursing, 1973).

There is no more devastating experience in the life of a family than the fatal illness and death of a child. It tears into the family's life as a functioning unit and confronts each family member with a crisis in coping with loss and grief. The shock extends from parents and siblings to involve grandparents, other family members and friends.<sup>111</sup>

With the steep decline in child mortality brought about by the developments in modern medical science, modern chemotherapeutic agents, improvements in living conditions and child care the death of a child has become a rare event, and perhaps for these reasons it is more difficult for parents to accept a diagnosis of terminal illness.

For parents, the death of one of their children, however inevitable, is and has always been an unrelieved tragedy; a child is a venture into the future, fraught with all their hopes, and his loss is for them often far harder to contemplate than their own death.

Often parents need and use the child psychologically—e.g., to complete their identity; to live out their unlived dreams; to fulfill what they were unable to fulfill. Thus, the threat of losing the child becomes a traumatic event. When death was an everyday event and people died at home, there must have been a general understanding, based on both experience and intuition, of how the bereaved could best

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<sup>111</sup> Jerry M. Wiener, "Reaction of the Family to the Fatal Illness of a Child," in Bernard Schoenberg (ed.) Loss and Grief, p. 87.

be supported; relatives, friends, clergy, physicians—all played appropriate roles. Nowadays the majority of the people die in hospitals, with a tabu on death, with the result that both the patient and his/her relatives are deprived of the consolation and support which familiar things and people provide.<sup>112</sup> In the community, instead of loving support the bereaved family is isolated. A mother voiced the comments of others: "People don't know how to handle you. They can't believe you survive. They don't know what to say. They stare—like I'm a sort of leper." Words that aptly put into focus the evasive, clumsy and fumbling way in which society reacts to death.<sup>113</sup>

Modern chemotherapeutic agents, for instance, have extended the average life expectancy of the leukemic child to more than two years and there is a growing number of children who have survived five years or longer. Long symptom-free periods of remission are quite common. On the other hand death is still considered the inevitable outcome of leukemia within a few years of onset, and the predictable unfolding of the illness, with its increasingly frequent relapses and even shorter periods of remission, serves to confirm the diagnosis and fatal prognosis. One can easily imagine the problems involved in accepting and adapting to such a situation in which you never know what the next day might bring. Successful adaptation requires that parents

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<sup>112</sup>J.A. Davis, "The Attitude of Parents to the Approaching Death of Their Child," Developmental Medicine and Child Neurology, VI (1964), 286.

<sup>113</sup>Margaret Atkin, "The Doomed Family," in Burton, Care of the Child Facing Death, p. 73.

maintain a dynamic balance between the tasks involving continued investment in the physical and emotional well-being of the child on the one hand, and the task of anticipatory mourning on the other.<sup>114</sup>

Reaction to the news of terminal illness in a child and a sibling may range from adaptive to temporarily disruptive, to more severely maladaptive. Each parent and sibling reacts to fatal illness individually, in a manner consistent with his own personality structure, past experiences, current crisis, and the particular meaning or special circumstances associated with the loss threatening him/her.

#### 6.4.1 The Parents

##### 6.4.1.1 Marital Relationship

A central consideration is the nature of the marital relationship. The consensus seems to be that if the marriage is a "good" one, the stress of the illness which may include a long separation between husband and wife, serves to draw the two partners closer together in their fight against a common enemy. However, I am also aware of apparently "good" marriages which totally disintegrated in the presence of terminal illness of a child.

During a time of such crisis as terminal illness of a child within a family, effective communication between husband and wife is

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<sup>114</sup>Edward H. Fluttermann et al., "Parental Anticipatory Mourning," in Schoenberg (ed.) Psychosocial Aspects of Terminal Care, pp. 247-248.

particularly essential. A great deal of support comfort and strength is needed by each spouse, one from the other, and the stability of the entire family unit depends upon the strength of the parents' relationship.

Ackerman<sup>115</sup> describes the healthy marriage as characterized by a

relatively clear awareness of strivings and values, positive in emphasis rather than defensive. Strivings and values would be shared to a reasonable degree by both partners and would be relatively realistic, stable, and flexible. There would be a reasonable degree of compatibility in the main areas of shared experiences—the emotional, social, sexual, economic, and parental areas. Conflict would not be excessive, would be under control, and would have mainly a realistic, rather than an irrational, content. There would be empathic tolerance of differences based on mutual understanding and equality and tolerance as well as residual immaturities of need that might be present in either partner. There would be a sharing of pleasure, responsibility and authority. There would be reasonable fulfillment of goals both for the relationship and for the further development of each partner as an individual. Each would be as much concerned for the welfare and development of the partner as for the self. Where differences exist, the mutual, unreserved acceptance of each partner by the other would make of these differences a stimulus for growth, both for the relationship and for each partner as an individual, rather than a basis for conflict or alienation. Actual performance in marriage would reasonably approximate goals. There would be a relatively high complementarity on a positive basis as husband and wife and as father and mother. There would be no significant trends toward isolation, disintegration, or regression.

There are, in contrast to this, many strained, alienated, fragile, or borderline marital adjustments. Here one will observe less than adequate mutual support, each parent reacting and coping in isolation. In many marriages consideration for the children has been

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<sup>115</sup> Nathan W. Ackerman, The Psychodynamics of Family Life (New York: Basic Books, 1958), p. 155.

the overt reason for the parents remaining together, but the children are covertly assigned responsibility for the parents' unhappiness or have become pawns in a parental power struggle. In such cases both children and parents will have an undue amount of mixed feeling toward each other.<sup>116</sup>

Even where the problems are not great, temporary marital stresses may arise from time to time, for example, if the child is unwell. The mother of a six-year-old cystic child said that at such times, when she hears the child coughing in the next room, she turns away from her husband, "I'm so worried I can't be with it—and then I don't seem to be treating him right either." Divided loyalties, feeling of sexual tension and strain, all make for greater difficulty in coping with treatment and maintaining the necessary aura of optimism.<sup>117</sup>

In his study Binger<sup>118</sup> discovered that fathers found many ways to absent themselves from painful involvement with their troubled families. This type of behavior is a coping mechanism and often indicates the father's need for additional support. Although others may look upon such behavior as expressive lack of interest and concern, it is a way of avoiding the pain of an ongoing involvement with the

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<sup>116</sup>Wiener, "Reaction of the Family . . . ," p. 89.

<sup>117</sup>Lindy Burton, "Tolerating the Intolerable," in her Care of the Child Facing Death, p. 23.

<sup>118</sup>Binger, "Childhood Leukemia," p. 416.

terminally ill child. According to Wold and Townes,<sup>119</sup> fathers are often estranged from the care of the leukemic child through lack of knowledge of current treatment and the added responsibilities at home. In addition, the clinical impression is that the fathers are delayed in their mourning process. This delay, relative to the mother's may contribute to intramarital stress. Mrs. L. stated, "I don't think Ralph accepted it right up to the day Peter died." Another father related that the easiest way for him to handle the problem was to seek no information about the child's condition because knowing very little helped him avoid thinking too much about the future.

Such avoidance, however, often leaves the mother bereft of much needed support.

Very often marital crises are precipitated by initial inability to accept the diagnosis and their own responsibility to face the problems ahead. In a 1969 American study, Bozeman found that 87% of families with leukemic children coped unsuccessfully with the many interpersonal conflicts superimposed on or accelerated by the stresses of the illness itself.<sup>120</sup>

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<sup>119</sup>David A. Wold and Brenda D. Townes, "The Adjustment of Siblings to Childhood Leukemia," Family Coordinator, XVIII:2 (1969), 156.

<sup>120</sup>Yvonne Craig, "Marital Crises and the Dying Child," Marriage Guidance (December 1974), 215-217.

#### 6.4.1.2 Reaction to the Illness

Reaction to the illness on the part of both the terminally ill child and the parents depend upon these background factors as they influence the parents' perceptions of what is happening to the child, themselves and the family. These factors affect the child's interpretation of his/her illness, his/her adaptive capacity and coping behavior. As used here, adaptive and coping behavior in the child and parent refers to the entire repertoire of defenses, characteristic reactions, social interactions, and behavior which are available to an individual in aiding him to master inner conflicts and environmental stresses. When presented with a major crisis such as terminal illness and death of a child, parents must have resources which help to temper the pain, in order to allow for continued contact with reality, and to keep them available at a time when the child has a heightened need for support and care.<sup>121</sup>

Parents react with shock and disbelief when they first learn that their child is dying.<sup>122</sup> They may lose total control of themselves or listen to it with outward calm and resignation. Many parents described this as the hardest blow they had to bear throughout the course of the illness. For many the diagnosis is a pronouncement of doom. Their consequent distress may so color their outlook and way of life that any extension of the child's life, provided by medical

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<sup>121</sup>Wiener, "Reaction of the Family . . . ," p. 89.

<sup>122</sup>Easson, The Dying Child, p. 66.



science, tends to be spent in the shadow of death, rather than a positive attempt to live the remaining days fully together.<sup>123</sup>

Often little effort is made to prepare parents for this dreadful news. One wonders if there exists an assumption that parents can cope with the truth about their children more easily than they can with the truth about themselves.<sup>124</sup> Binger<sup>125</sup> found that during the first days or weeks after hearing the diagnosis most parents experienced symptoms of physical distress, depression, inability to function, anger, hostility and self blame (anticipatory grief reactions), followed by acceptance and resolution to meet the needs of the child.

Parents are not only struggling with their own emotions and problems that arise within their family, but very often they have to cope with reactions of the community, with the problem of hospitalization and dealing with medical personnel.

Studies<sup>126</sup> indicate that families, even whole neighborhoods react profoundly to the diagnosis of cancer, professing ignorance on the fact that cancer is frequently seen as a family disgrace. Not being aware of the social phenomena misunderstandings pile up. The doctor repeating "medical facts" and the family pleading with him/her

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<sup>123</sup>Burton, "Cancer Children."

<sup>124</sup>Bowers, Counseling the Dying, p. 112.

<sup>125</sup>Binger, "Childhood Leukemia . . . ," p. 415.

<sup>126</sup>Kenneth L. Artiss and Arthur S. Levine, "Doctor-Patient Relation in Severe Illness," New England Journal of Medicine, CCLXXXVIII:23 (1973), 1213.

for social solutions to their community problems. Very often doctors misunderstand the parents' request for information about the dying child, responding to the medical data, when the parents want to discuss their own sense of guilt and complicity in the cancer.

Young physicians voiced an almost universal fear of entering into "real life" discussions with patients or with their families. "If I once let it get started, I'll never get anything else done." Furthermore, the physicians demonstrated a tendency, when working with the parent, to taking up a strong adversary position vis-a-vis the parent as interfering with his treatment efforts.<sup>127</sup> One can hardly blame parents for feeling guilty, burdened, and confused as to how they should behave. In spite of a strong impulse to run from the problem they generally do not withdraw.<sup>128</sup>

We may often find complete denial by parents, raising doubts about the diagnosis, seeking second opinions and repetitively questioning the doctor who made the diagnosis. After the initial denial of the diagnosis gives way to gradual acceptance of the illness, the parents may indulge in considerable activity. Cases are known where such activity took parents away from the terminally ill child. In other instances the child may become the pivot of the parents' attentions, receiving care in excess of physical needs. Many mothers adopt patterns of clinging to the child physically and show increasing

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<sup>127</sup> Ibid., p. 1212.

<sup>128</sup> Barbero, "The Child, Parent, and Doctor in Death from Chronic Disease," p. 284.

need for close body contact. Smothering and overprotection should be avoided.<sup>129</sup>

Anger arises because despite everything the parents have done the child deteriorates. They realize that they feel angry at the defenceless ailing child and this produces guilt. Inevitably guilt and anger will be directed toward the medical personnel caring for the child. This is only natural because they need some way to express and work out this anger. Frequently this resentment is expressed toward other members of the family.

When I come back from the hospital I can't bear the other children near me. It seems such an insult to her to be cuddling them. I hate to see other children in the street too, being happy. I keep thinking, 'Why couldn't it have been an unwanted child.'<sup>130</sup>

Parents may attack each other in violent anger. Brothers and sisters may be irritable and nasty to each other. Often bitter accusations are made—sometimes accusations that the child's illness has been caused or allowed by negligence within the family. Illogical, resentful statements can be made, violent threats can be expressed—and all because these family members care deeply, grieve greatly and are angry because the dying child is leaving them.

Sometimes sorrowing relatives turn their mourning anger in on themselves. The sad father berates himself for not being present when the child showed the first symptoms, for not taking the child to a doctor immediately—he is attacking himself and he will become

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<sup>129</sup>Burton, "Cancer Children."

<sup>130</sup>Burton, "Tolerating the Intolerable," p. 19.

depressed. The sorrowing mother feels she has failed the child—if only she had fed him/her better he would have been stronger and thus could have resisted leukemia. She takes out her mourning anger on herself and she is liable to become profoundly depressed. Brothers and sisters may feel guilty because they were not better protectors; they feel increasingly worthless and bad.<sup>131</sup> Although observers disagree as to the intensity and significance of guilt,<sup>132;133;134</sup> all agree that guilt feelings are a normal part of parents' reaction.

Friedman et al.<sup>135</sup> found that younger children with leukemia frequently openly rejected their parents, making such statements as "I hate you and I don't ever want to see you again!" with the result that parents would feel that in some way they have failed their child. This behavior appeared after the child had been ill for some time and it seemed in part related to the parents' inability to prevent painful procedures and prolonged hospitalization with consequent damage to the usual childhood faith in parental omnipotence. Furthermore, the children may have a sense of their dependence on the medical

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<sup>131</sup> Easson, The Dying Child, p. 68.

<sup>132</sup> Stanford B. Friedman, "Care of the Family of the Child With Cancer," Pediatrics, XL (September 1967)

<sup>133</sup> Joseph M. Natterson and Alfred G. Knudson, "Observations Concerning Fear of Death in Fatally Ill Children and Their Mothers," Psychosomatic Medicine, XXII (1960)

<sup>134</sup> Stanford B. Friedman et al., "Behavioral Observations on Parents Anticipating the Death of a Child," Pediatrics, XXXII (October 1963)

<sup>135</sup> Ibid., p. 615.

and nursing staff and were fearful of expressing hostility directly toward these individuals. In requests the children would bypass their parents who would feel that they were no longer important to the children. Even during periods of remission at home, the child would say: "Call my doctor and ask him," reflecting his awareness of his parents' limitations.

Parents may experience a total lack of affect and will be able to talk realistically about their children's condition and prognosis with relatively little evidence of any emotional involvement. Often this reaction is being described as "being strong," though occasionally this behavior was interpreted as reflecting a "coldness" or lack of sincere concern. Parents who are aware of their paucity of emotional feelings may explain it by saying "I could not break down in the presence of the child and the doctor."

Occasionally parents may intellectualize, as if they are trying to master the situation through complete understanding. They attempt to discuss the illness in a detached and highly intellectual manner.

#### 6.4.1.3 Anticipatory Grief

Anticipatory grief<sup>136,137</sup> constitutes a major task in the adaptation of parents to the expected loss of a child. Mourning in-

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<sup>136</sup>Binger, "Childhood Leukemia . . . ," p. 416.

<sup>137</sup>Burton, "Cancer Children," p. 1041.

variably begins before death. The work of mourning involves gradual relinquishing emotional investment in the dying or dead person. Even while maintaining hope and mastery activities throughout the course of the child's illness, the parents usually begin disengaging from the child before his/her death. Such disengagement is emotionally hazardous since it runs counter to the task of caring for the child's needs and promoting his/her development. Parents are, therefore, particularly vulnerable to guilt which may result from the emotional detachment that accompanies anticipatory mourning. Compensatory restitutive efforts, on the other hand, may lead to symbiotic clinging and stifling overinvolvement with the sick child, neglect of one's own needs as well as those of other family members, general family disruption, and the inability to deal with the demands of reality.

Flutterman<sup>138</sup> suggests the sequential emergence of the following part processes of anticipatory mourning.

- (1) Acknowledgement: Becoming progressively convinced that the child's death is inevitable.
- (2) Grieving: Experiencing and expressing the emotional impact of the anticipated loss and the physical, psychological, and interpersonal turmoil associated with it.
- (3) Reconciliation: Developing perspectives on the child's expected death which preserve a sense of confidence in the

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<sup>138</sup>Flutterman, "Parental Anticipatory Mourning," pp. 251-252.

worth of the child's life and in the worth of life in general.

- (4) Detachment: Withdrawing emotional investment from the child as a growing being with a real future.
- (5) Memorialization: Developing a relatively fixed conscious mental representation of the dying child which will endure beyond his/her death.

#### 6.4.2 The Siblings

There has been some interest and concern focused on the dying child and his/her parents and it is right that it should be so, for there are few situations more tragic for the parents to face than this. Much less concern has been shown for the terminally ill child's brothers and sisters, and yet these children are important, for it is they who, when they grow up and have their own families, are likely to have to cope with situations that in some way will remind them of this time.<sup>139</sup>

In a study done by Binger<sup>140</sup> he found that in approximately half of the families one or more previously well siblings showed significant behavioral patterns that indicated difficulty in coping. Problems described by parents included an onset of severe enuresis,

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<sup>139</sup>Mary Lindsay and Dermot MacCarthy, "Caring For the Brothers and Sisters of a Dying Child," in Burton, Care of the Child Facing Death, p. 189.

<sup>140</sup>Binger, "Childhood Leukemia . . . ," p. 416.

headaches, poor school performance, school phobia, depression, severe separation anxieties and persistent abdominal pains. Several siblings complained of the preoccupation of parents and friends with the ill child. Often siblings had feelings of guilt and fear that they too might suffer a fatal illness; they misinterpreted their parents' preoccupation with the sick child as rejection of themselves. In their own way they had anticipatory grief reactions.

During such times they become essentially motherless, their mother not only being emotionally drained by her ordeal, but often having little actual time left for the other children (this will be even worse if the hospital is some distance away.) In her absence, the children are often left with neighbors, or even distributed among relatives for prolonged periods. The remaining children often lose not just their mother's love and concern but her very physical presence. When available she is rushed, burdened, sapped and irritable, and, should the children complain, they are likely to draw a hasty, guilt-inducing retort. Illness, too, may come to be seen as the only route to the mother--but far more crucial is her physical and psychological absence and almost inevitably disturbed state. As the children now turn to their father they find little emotional support, for he is bereft of his wife, has heavily increased responsibilities and is struggling to suppress his own anguish.<sup>141,142</sup>

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<sup>141</sup>Albert C. Cain et al., "Children's Disturbed Reactions to Death of a Sibling," American Journal of Orthopsychiatry, XXXIV:4 (July 1964), 749-750.

<sup>142</sup>Beatrix Cobb, "Psychological Impact of Long Illness and



The reaction of siblings will depend on their age, maturity, ability to comprehend and integrate the meaning of the illness, the particular relationship of the siblings to the ill child, the siblings' own place and adjustment within the family, and perhaps most importantly, the honesty and appropriateness with which the parents communicate with them about the ill child and the nature of the problem. Much depends on how they are included, as part of the family, in the adaptation to the crisis.<sup>143</sup>

Siblings may perceive as quickly or quicker than the ill child that something serious is wrong. The very young may simply miss their playmate, whereas an older child will experience and share parental concern and anxiety. Older children and adolescents can comprehend fairly completely the full implications of the illness and the parents can be frank in sharing information and answering their questions. For younger children with less mature conceptual capacities, too much and too complete an explanation will confuse instead of clarify. Whatever is told the siblings by way of explanation and in answer to their questions should be the truth. Parental judgment, individual needs, and the family's values will shape the specifics and determine the extent of the truth to be shared, but the truth it should be.<sup>144</sup>

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Death of a Child on the Family Circle," The Journal of Pediatrics, XLIX:6 (December 1956), 749.

<sup>143</sup>Wiener, "Reaction of the Family . . . ," p. 96.

<sup>144</sup>Ibid.

The closeness in age reinforces any tendency to fear for one's own health and seriously challenges the child's belief that only old people die. The intense interpersonal relations between brothers and sisters—including their fights and quarrels—also add to the trauma of losing a sibling. Previous expressions of hostility, real or imaginary, may haunt the siblings of a fatally ill or deceased child. In the young child feelings of omnipotence may, in a sense be confirmed by the disappearance of a brother or a sister. She/he assumes responsibility for his/her wishes and she/he believes that his/her wishes go into effect immediately. This imagined power frightens him/her now that his/her terminally ill brother/sister did "disappear" and she/he may feel responsible for his/her sibling's fate. Such thoughts may be further strengthened by the apparent abandonment by his/her parents, who are preoccupied with their loss.<sup>145</sup>

It is quite natural for parents and other relations to over-indulge a seriously ill child and although this is at first acceptable to the rest of the family, jealousy may result if it continues once the child returns home during a remission. It is important not to punish the well children for being well and, however difficult it may be, to treat the children equally during a remission and at all times to keep the relationship with the children open, honest, warm and full of love.

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<sup>145</sup>Friedman, "Management of Death of a Parent or Sibling," p. 782.

### 6.4.3 The Extended Family

Friedman<sup>146</sup> found in his study that the terminally ill child's grandparents tended to be less accepting of the diagnosis than the parents, with more distant relatives and friends challenging reality even more frequently. The grandparents not only displayed more denial than the parents, but often appeared more vulnerable to the threatened loss of the loved child. Therefore many of the parents felt that they had to give emotional support to the grandparents at the time when it was most difficult to assume a supportive role.

### 6.5 Pastoral Care of the Family

When one member of a family is severely ill, the entire family becomes sick to a degree. When a beloved child dies, it is almost a truism that a little of every member of his family dies.<sup>147</sup> After the diagnosis of terminal illness in the child, the family experiences severe emotional trauma. Their world turns upside down. Old patterns of living and communicating begin to disintegrate. What was considered important in the past seems trivial now. Old priorities and basic beliefs are being questioned and reevaluated.

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<sup>146</sup>Friedman, "Behavioral Observations . . . ," pp. 618-619.

<sup>147</sup>Paul Patterson, "The Use and Misuse of Psychopharmaceuticals By the Pediatrician in the Care of the Dying Child and His Family" in Goldberg, Psychopharmacologic Agents For the Terminally Ill and Bereaved, p. 291.

There is an empty chair at the table; there is an empty bed in the room. The voice that became such a familiar sound and so very much loved and appreciated is not heard anymore. The sneakers that rushed up and down the stairs a thousand times every day are in the closet. She/he that is loved so much and cared for by so many people finds him/herself on a strange bed, in a strange environment, surrounded by strange people in white—terminally ill.

The daily organized and routine way of living changed into chaos. Mother spends most of her time in the hospital, father is rushing to and fro. There is no time for sharing and just being together any more. The family may become emotional strangers to each other in a strange home.

The hospitalization of a child adds anxiety and tension. Many other parents and children have had indescribable experiences in our modern hospitals and consequently have suffered immensely.<sup>148</sup> Experiences like this become known throughout the community.

The parents experience a tremendous amount of difficulty to get a personal interview with the specialist. The resident doctor on the ward is polite but not willing to become "involved." After a few hours the parents begin to feel that they are tolerated on the ward, at the bedside of their child, but that they don't really belong there. They feel isolated and rejected.

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<sup>148</sup>Robertson, Hospitals and Children.

The news that their little boy or girl is terminally ill with cancer spread quickly through the community and suddenly the parents find a tenseness in the old relaxed atmosphere and open communication which existed in the past. After a day or two the family find themselves isolated and alone within their own neighborhood, sometimes even frowned upon;—the lepers of our modern society!

The pastoral care of the families with terminally ill children is just as neglected as the comprehensive care of the child and the family in the hospital. The task is an extremely difficult and complicated one! In some way the majority of adults eventually manage to cope, but the siblings have to bear the brunt of the irresponsibility and negligence of the church and the pastors!

Much evidence has emerged from psychiatric work with child and adult patients of the destructive and permanently scarring effect of confused and unresolved mourning experiences in childhood. The loss of a sibling or a parent in early childhood is particularly damaging to the development of the bereaved person. This can even apply to a brother or sister who has died before his/her own birth and who will often continue to be part of the family as a powerful ghost sibling. Indeed, the experience of early loss of a sibling, if left unresolved, can be revived painfully at critical times in later life—when becoming a parent, during early child rearing, the illness of a child, or the death of a close relative.<sup>149</sup>

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<sup>149</sup> Bianca Gordon, "An Interdisciplinary Approach to the Dying Child and His Family," in Burton, Care of the Child Facing Death, p. 155.

In a study done by Binger,<sup>150</sup> he found that in approximately 70% of the families one or more members had emotional disturbances, after the death of a sibling, that were severe enough to interfere with adequate functioning and required psychiatric help. None had needed or used such help before.

The problem facing the pastor who works with terminally ill children is the problem of assisting them and their parents as well as the siblings to live as completely and well as possible during the ordeal of terminal illness and after the death had occurred. Is it possible and if so, how can it be done?

After admission of the terminally ill child to the hospital the hospital chaplain has the responsibility, not only to visit the patient, but to make contact with the parents as soon as possible. If they are not with the child it may be a difficult task to get hold of them, but it is well worth the effort to do it as soon as possible. The parish minister will most probably know the family and it is crucial that he visit with them as soon as possible. This may be either at home or in the hospital. During this meeting with the parents, if possible with the whole family, the pastor must use all his expertise and skill to evaluate the situation objectively and sensitively. This will provide an excellent opportunity to evaluate the family system<sup>151</sup> in operation. The pastor will be sensitive to

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<sup>150</sup> Binger, "Childhood Leukemia . . . ," p. 417.

<sup>151</sup> William J. Lederer and Don O. Jackson, The Mirages of Marriage (New York: Norton, 1968), p. 87ff.

how they communicate and relate to each other and how they operate in relation to each other and other systems. In an atmosphere filled with anxiety and tension and much emotional pain the pastor will detect weaknesses, areas of conflict and anxiety. At this point the pastor will function in a strong supportive role and he will be sensitive to the demonstrated needs that remain unexpressed.

Having just heard the diagnosis the parents will still be in a state of shock and will react with grief. The pastor needs to exercise great patience. Tact and time are needed to properly and adequately care for the parents, siblings, patient and the extended family. The family should be allowed the anticipatory grieving period—which involves a concentration of interest and energies, self-examination, self-condemnation and guilt. The family need to go through these processes in their own time and they need permission to do so. They must be allowed to voice their guilt since too large a burden of guilt would hinder the successful resolution of the grief process, and any further guilt would probably result in less ability to function effectively in caring for the siblings in the future. They may be struggling with many questions: "Should I have called the doctor sooner? Did the child inherit the disease from us?" etc. If the pastor discovers that the parents still have many questions (medical) surrounding the illness and have difficulty in getting an appointment with the specialist he could serve as a mediator between the parents and the specialist. I have never been denied a request on behalf of the parents to get an interview with the specialist or doctor. In hospitals where the pastor is considered a member of the

team the specialist will probably invite him to attend the meeting if the parents so desire. Parents usually appreciate the presence of this one member of the team who is more accessible. It is important that the parents will understand the course of the illness, the prognosis and the anticipated procedures in treatment as soon as possible, for parental fantasies are often much worse than actual fact.

The quality of the relationship which is established between the pastor and the family during this time of the illness will greatly determine the role of the pastor during the final phases of the illness and even after death had occurred. I have found parents very appreciative and very open to any person who reaches out to them during this time in a quiet and unobtrusive way, willing to share their ordeal and accompanying them on their path.

Binger reports on a study done that he found that if there were a meaningful relationship with the clergy before the illness it seemed to continue throughout; de novo introduction of clergy at this critical time seemed to be of little help.<sup>152</sup> My own experience contradicts his conclusions. I believe that it depends almost entirely on the pastor; his/her sensitivity, his/her humaneness, his/her empathy and his/her willingness to enter respectfully into their lives when invited to do so. Some of the most meaningful experiences I have had as a hospital chaplain were in situations where

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<sup>152</sup>Binger, "Childhood Leukemia . . . ," p. 416.



I had absolutely no contact with the family before the final critical days or hours. During these long and lonely hours they welcome the presence of another human being.

Parents may turn to each other for mutual help, support and care. The quality of this support seems to relate the state of their marriage. Other parents may experience severe loneliness, handling their grief on their own and unable (often unwilling) to be helpful to the spouse. When the terminal illness stretches out over a long period the pastor finds himself in an excellent position to enter into a counseling relationship with the parents. Once a relationship has been established and the parents trust the pastor, they may also entrust the pain in their marriage-relationship to him. Whether the pastor will enter into conjoint marital therapy<sup>153</sup> or see them individually will depend on his/her evaluation of the situation. At other times it may be wise to involve the whole family (parents and siblings) in counseling.

In crisis situations where the pastor identifies disturbed or pathological behavior or even (self) destructive behavior in a family member she/he may use the A.B.C. method of Warren Jones of crises intervention<sup>154</sup> in his counseling with the person. The pastor will challenge the person to respond to the crises in the most appropriate way with the resources available to him/her

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<sup>153</sup>Virginia Satir, Conjoint Family Therapy (Palo Alto, CA: Science and Behavior Books, 1964).

<sup>154</sup>See Appendix A.

The father who copes with this ordeal by absenting himself from the painful involvement with his troubled family and consequently expresses a lack of interest and concern may be helped to express his painful feelings and to look at the effect of his behavior on his family.

It would be helpful if the pastor knows each member of the family, knows how they relate to each other, knows how they react to the diagnosis, knows how their grief process begins and how they cope, knows what they believe about life, death and religion, knows how they responded to previous crisis and is able to identify the current burdens and sources of support.<sup>155</sup> I want to point out that this is background information and it is not necessary for helping a troubled family. The pastor will do a disfavor to the family and to himself when struggling to get "information" from a family in crisis. He should rather respond to the "here" and "now" and deal with that situation.

Illness permeates and transforms family life. The strains imposed by it is often intense. Very often family members experience aggressiveness and anger because of the massive threat and frustration of the child's illness. Since few can tolerate undirected, free-floating anger, it tends to be directed towards a significant object (the terminally ill child who is helpless and excluded). The marital partner, siblings, members of the team may become targets. The clergy,

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<sup>155</sup>Binger, "Childhood Leukemia . . . ," p. 418.

the church and God may become subject to the angry protest: "I'm unable to continue believing in a God who could act as cruelly as this!"

Such anger can exert a destructive influence on necessary relationships and may alienate the parent from significant sources of help and support. It can, therefore, have preventative as well as therapeutic import if the pastor can help the parent contain his/her anger by exploring and ventilating it within the counseling sessions, and by finding appropriate channels of discharge outside.

Parents can constructively utilize aggressive energy in fighting on behalf of the child: mastering the treatment regimen, raising funds to support medical research, etc. However, support and guidance are needed in finding such outlets.<sup>156</sup>

Some parents are initially reluctant to accept the fact that the mental and emotional welfare of their surviving children should be discussed, and often even show irritation at the pastor's concern. While the terminally ill child is still alive their attitude is "Do everything you can for him and don't concern yourself with our healthy children." They are clearly afraid that the pastor's concern will take away attention from the dying child. Moreover, our concern may suggest to them that their other children are also thought to be at risk, and that professional scrutiny may reveal that this is so. Their resistance stems from their own underlying anxiety about the

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<sup>156</sup>Audrey T. McCollum, "Counseling the Grieving Parent," in Burton, Care of the Child Facing Death, pp. 182-183.

physical and mental well-being of their surviving children. In a gentle way the parents could be helped to recognize the importance for concern about the mental and emotional welfare of the siblings, for the effects of bereavement are less obvious, more complex and frequently more far reaching.<sup>157</sup>

The parents often clearly would not allow the siblings to talk about the event. They rush in with heavy repeated reassurances, quickly label it all as not "very serious," and cut off any possibility of the child's telling them what is on his/her mind. In most cases the siblings know what is happening, expect the worse and often experience guilt feelings, assuming responsibility for the events. Parents should be encouraged to bring the siblings to the hospital or to the clinic when the patient has a remission. This will not only introduce the siblings to the world of the terminally ill child, but it can provide excellent opportunity for the pastor to meet with the siblings. In this way they can get acquainted and the pastor could even arrange to spend a part of their time at the hospital in play therapy while the parents visit with the terminally ill child. The pastor may even visit the family at home, give time and attention to the siblings and build a trusting open relationship. It is necessary to observe the children in the presence of their parents. This may help to determine the degree and quality of communication between parents and siblings. In dealing with older siblings a

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<sup>157</sup>Gordon, "An Interdisciplinary Approach . . . ," p. 154.

therapeutic technique would attempt to deal with the threatened loss by a forthright approach and attention to details of the reality situation. The pastor will allow the sibling to determine how far he wants to go, how much he wants to know. If the sibling chooses to use denial as a coping mechanism, the pastor has to respect it. Gentleness, loving care, warm empathy, honesty and sensitivity are the basic qualities needed by the pastor.

If the pastor is a parish minister she/he will use all the resources available within the church and the congregation to support the family, the parents as well as the siblings. The basic principles in dealing with the family will remain the same, whether used by the pastor who is a hospital chaplain or the pastor who is a parish minister.

If it is a lingering illness with frequent remissions the family should be involved in group therapy.<sup>158,159,160</sup> It need not be called therapy. Parents of leukemic children can meet once a week in a group where they can share information and problems with each other. The pastor (group-leader) can practice "crisis" intervention during and after sessions. When a family is in trouble she/he can refer them. The pastor need not do everything him/herself. It will

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<sup>158</sup> Clinebell, The People Dynamic.

<sup>159</sup> Robert C. Leslie, Sharing Groups in the Church (New York: Abingdon Press, 1971)

<sup>160</sup> C. Grafton Kemp, Small Groups and Self Renewal (New York: Seabury Press, 1971)

be physically and humanly impossible. She/he can and must use all the means available to him/her to support the family. It could be a psychiatrist, social worker, play therapist or even lay people with the potential to be helpful in that particular situation.

During a time of terminal illness in a home the parents ask many questions. One most frequently heard is "why?" "Why did God do this to me?" "Why did God allow it?"

In our present time of declining religious belief many parents are unable to see a divine purpose in the event, and they construct explanations from a composite of scientific facts, anecdotal information learned from others and fragments from their own fantasies. This is however, never completely satisfactory and they will struggle with these questions in their minds day after day after day. They seldom find peace.

There is little comfort in saying that it was meant to be and it is blasphemous to claim that it was God's will. All one can do is let the parent talk about his feelings and point out where the train of events was taken out of our hands. Often all one can do is point out that facts, however terrible, must be accepted, but that one's obligations do not stop. Showing that a husband must support his wife and vice versa, and that both are needed by the remaining children, might turn the thoughts to more constructive paths.

In many cases guilt and/or anger are behind these questions. The pastor has to be a sensitive listener and deal constructively with these feelings on a "here and now" level. Cicely Saunders feels that there is a very great difference between those who are without

faith and those who trust that there is a meaning in the whole of existence, and that short life, so incomplete here, will find its fulfillment. But both may need the pastor's help to move on from bitterness and regrets into the place where good memories overcome bad ones. A child will go on living in the parents' thoughts even if they do not believe his life continues anywhere else.<sup>161</sup>

In times when a parents' world crumbles, when one experiences Godforsakenness, when prayers seem to become empty words, the pastor always has to be available and present when necessary. Presence alone can incarnate understanding, loving and caring. The pastor is humble in the knowledge that he is present in the name of Jesus Christ, our Lord. When one can learn to trust a person again, when one can experience the love and closeness of another human being, then perhaps one can learn to trust God again and accept that all love is from Him. Terminal illness in a family, however traumatic, can be a source for spiritual growth. The sincere concern and care of the pastor can, by the grace of God, lead the person to greater maturity, to more fulfillment.

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<sup>161</sup>Saunders, "The Management of Fatal Illness in Childhood."

## CHAPTER 7

### THE TERMINALLY ILL ADULT

I was a dying man and people didn't want to be around me. They were afraid they might say the wrong thing . . . people talked in whispers when they came into my room to see me.

I still didn't want to talk to my wife about it . . . I just didn't want to worry her. Many nights she slept downstairs on the couch in the den and later I found it was because she was crying herself to sleep most nights.

I quit disciplining my children. I didn't want them to remember me as a father who punished them. And whenever I looked at them, I couldn't help but think I wouldn't even probably see my four-year-old son enter school or my oldest son graduate.

I wondered why all this had happened to me. I really wasn't that much of a sinner. I could think of quite a few other people who qualified for cancer more than I if it was punishment of some kind. And I always thought of death. It was in the back of my mind, lurking there. I thought of life after death. Would my wife join me in heaven as she was when I died? Would my children be older than me? Crazy questions, maybe, but I thought about them. Above all I worried about what would happen to my wife and children after I died.

I had to talk to someone. I knew I couldn't continue on the way I was doing. The family I loved so much was not a family any longer. The barbecues were over; we didn't listen to music any longer, or do any of the things we used to do.

The thought occurred to me that I could commit suicide! But I wanted to spend one more Christmas with my family. Meanwhile I felt like a burden. And I felt guilty . . . I had cancer! I remember once getting my drink in a paper cup when everyone else had glasses. I guess they were trying to tell me something.<sup>1</sup>

A survey<sup>2</sup> done in 1967 in England indicated that one death in ten was considered to be unexpected, generally due to vascular

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<sup>1</sup>Orville E. Kelly, "How to Face Life When You're Dying" (Burlington, IA: Make Today Count) At the time of this writing Orville Kelly is still terminally ill.

<sup>2</sup>John Hinton, Dying (Baltimore: Penguin Books, 1972), p. 66.



disorders. The majority of people will have a terminal period requiring special care lasting a few days or a week; usually not exceeding three months. There are various reasons for this; most important perhaps, the recent advances in medicine which have resulted in increasing numbers of patients being treated for chronic illness over longer periods of time. For patients with cancer, for example, earlier detection, more strenuous surgical treatment, new chemotherapeutic agents, and better combinations of treatment have increased the chances of survival and the period of illness preceding death.<sup>3</sup>

The manner in which any individual will react to a diagnosis of terminal illness will depend upon his ability to adapt to a situation of threat. Ego strength is the vital factor which determines how sturdily the fortress of self is built—how well it can endure the psychic shock, physical disability, pain and other eroding aspects of terminal illness. Ego strength represents the sum total of intellectual and emotional maturity of an individual.<sup>4</sup>

Verwoerd<sup>5</sup> claims that religious convictions can act as a gauge of the patient's emotional reserves, particularly if religion

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<sup>3</sup>Bernard Schoenberg and Robert A. Senescu, "The Patient's Reaction to Fatal Illness," in Bernard Schoenberg (ed.) Loss and Grief (New York: Columbia University Press, 1970), p. 221.

<sup>4</sup>Adriaan Verwoerd, Communication With the Fatally Ill (Springfield, IL: Thomas, 1966), p. 15.

<sup>5</sup>Ibid., pp. 15-16.

has played a significant role throughout his/her life. While religious belief is certainly no guarantee of freedom from anxiety, a consistent lifelong faith without elements of extremism or fanaticism points to stability of character. At the same time, of course, it must be remembered that a patient without religious faith is not necessarily unstable.

The intellectual resources of the patient are important in determining his/her overall capacity for comprehension and, consequently, the level on which communication in general should be conducted—bearing in mind, of course, that the patient's ability to understand is colored by his/her emotional attitudes. Other factors that may influence the patient's reaction to the diagnosis of terminal illness are the general patterns of behavior, family relationships, economic situation and what is known about the illness in general. No two people will ever react in a similar way; therefore, a prediction of the reaction is impossible. Eric Fromm said: "Environment is never the same for two people, for the difference in constitution makes them experience the same environment in a more or less different way."<sup>6</sup>

It is said that people die as they live. There is some truth in this.<sup>7</sup>

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<sup>6</sup>Eric Fromm, Man For Himself (New York: Fawcett, 1965), p. 69.

<sup>7</sup>Frederic P. Herter, "The Right to Die in Dignity," in Austin H. Kutscher (ed.) Death and Bereavement (Springfield, IL: Thomas, 1974), p. 17.

Elizabeth Kübler-Ross once described a woman who said to her "I've been angry and rebellious my entire life! Why should you expect me to change when I'm dying?"<sup>8</sup> Eissler<sup>9</sup> agrees with this when he says: "The idea—often expressed by philosophers and well supported by the psychoanalytic conception of the personality—that the whole preceding lifetime is reflected in the terminal phase of a human being seems to be correct."

Certainly if a person is dying it is no time for us to press for major changes in life style. However, a change may come, depending on how much the new circumstances serve as a catalyst.

I remember Mrs. K. who told me: "I've been the most impossible person to live with. You should ask my husband, but since the doctor discovered the shadow I've changed."

### 7.1 Handling Different Age Groups

Obviously, the medical team's approach to the terminally ill patient will vary and change according to whether the patient is young or old, easily frightened and fearful, or stoical and acquiescent.<sup>10</sup> In Chapter 6 I emphasized the differences in the concept of death and the coping behavior of the terminally ill child at

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<sup>8</sup>Marjorie Casebier McCoy, To Die With Style (New York: Abingdon Press, 1974), p. 59.

<sup>9</sup>Kurt R. Eissler, The Psychiatrist and the Dying Patient (New York: International Universities Press, 1973), p. 263.

<sup>10</sup>Walter C. Alvarez, "Care of the Dying," Journal of the American Medical Association, CL:2 (1952), 88.

different ages. I pointed out that teenagers and young adults who are dying generally are more conscious of what is happening and react much stronger to the threat of death. Many are reluctant to die before they have had a chance to live!

I have witnessed many young people in their twenties and thirties just settled in their new home, happy and satisfied with their job and with their progress socially and financially, eventually able to have their long anticipated child, or perhaps by this time two or three children, who became terminally ill. It is difficult to find words that can adequately describe the ordeal, the anger and resentment, the sadness and distress at having to go and leave a greatly loved spouse and child or children. According to Alvarez<sup>11</sup> there are those cut off in the full vigor of life, who make no protest. He quotes a poem written by Hans Zinssor, the bacteriologist, who died in the prime of his life because of leukemia and who, concerned over the future loneliness of the loved one he was about to leave wrote for her the following sonnet:

When I am gone—and I shall go before you—  
Think of me not as your disconsolate lover;  
Think of the joy it gave me to adore you,  
Of sun and stars you helped me to discover.

And this still living part of me will come  
To sit beside you, in the empty room.

Then all on Earth that Death has left behind  
Will be the merry part of me within your mind.

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<sup>11</sup>Ibid., p. 88.

I have been with terminally ill patients in their midyears, struggling with the reality of their impending death. The first phase of adult life has been lived. Family and occupation have become established, parents have grown old, and children are at the threshold of adulthood. Youth and childhood are past and gone, and demand to be mourned. The achievement of mature and independent adulthood presents itself as the main psychological task. This time is really the prime of life; the stage of fulfillment!<sup>12</sup> I visited Mrs. S. who was 47, terminally ill and very depressed.

Mrs. S.: This is so unfair, unjust . . . so terribly sad . . . sad. (silence)  
 Look at my hands . . . I worked hard; my husband and I worked hard to give our three children the best and send them out, into life, well equipped. They are all out of the house now. There are so many things we always wanted to do; travel, good shows, opera, symphony. Just relax and be together; discover each other once again. He used to say: 'It will be a second honeymoon—our marriage all over again . . .' (silence . . . cry) And . . . and now this!!

During recent years a number of books were published by people in their midyears, describing the experience of terminal illness and

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<sup>12</sup>Elliott Jaques, "Death and the Mid-Life Crisis," International Journal of Psychoanalysis, XLVI (1965), 506.

impending death<sup>13</sup> for themselves and the experience of the dying of a spouse.<sup>14,15,16,17</sup>

Less distressing, usually, is the problem of slow death when it comes to the aged, to those whose race has been run, to those who had lost a spouse and are lonely, at times longing to die. Other elderly persons who, for years, have suffered the tortures of a failing heart, crippled joints, or a series of strokes are often glad to go. Some keep asking, "How much longer has it got to be?" They want to get on with their job of dying.<sup>18</sup> William Hunter, the great anatomist who died after completing a long full life retained his consciousness to his last breath and just before he died he whispered: "If I had strength enough to hold a pen, I would write how easy and pleasant a thing it is to die."<sup>19</sup> However, I have been with elderly people, fighting death until their last breath,

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<sup>13</sup> Stewart Alsop, Stay of Execution (London: Lippincot, 1973)

<sup>14</sup> Jocelyn Evans, Living With a Man Who is Dying (New York: Tapunger, 1971)

<sup>15</sup> Margaret Woods Johnson, We Lived With Dying (Waco, TX: Word Books, 1975)

<sup>16</sup> Marlena Frick, All the Days of His Dying (London: Allison and Busby, 1972)

<sup>17</sup> Lynn Caine, Widow (New York: Morrow, 1974)

<sup>18</sup> Alvarez, "Care of the Dying," p. 88.

<sup>19</sup> Alfred Worcester, The Care of the Aged, the Dying and the Dead (Springfield, IL: Thomas, 1961), p. 43.

frustrated, angry, anguished—an incomplete life! Dying indeed in the same way they have lived their lives!

## 7.2 Reaction to Hospitalization

In this century the rapid development of the science of medicine and its application to the physical care of hospitalized patients has been impressive. However, there has been relative inattention to the problem of the emotional needs of the hospitalized patient. Patients with histories of painful, frightening, or incapacitating illnesses in childhood or during previous hospitalizations can be expected to approach the current hospitalization with heightened fear and suspicion.<sup>20</sup>

I visited a twenty-two year old man just admitted to the hospital. My presence helped him to verbalize some of his feelings about hospitalization,

I'm very lonely. And I'm scared. I'm filled with the feelings of a child who hurts and hurts and hurts . . . .  
I remember my parents leaving me at a hospital when I was five years old. It was hell! They just left me. I thought they would never return. I cried and cried. I can still see them walking away, leaving me all by myself in the bed . . . .

At the moment when most persons probably want individualized attention and sympathetic understanding, they are likely to find themselves confronted with a clerk who asks, in a matter-of-fact manner, for information that they may even resent as trespassing upon

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<sup>20</sup>Robert G. Wright and Thomas H. Holmes, "Psychological Aspects of Hospitalization," in Harold I. Lief et al., The Psychological Basis of Medical Practice (New York: Harper & Row, 1963) pp. 219-220.

their private lives. Discussion of how and when the hospital bill is to be paid before admission is often disturbing to the rich and poor alike. Once the admission data have been obtained an aide bustles the patient off, generally accompanied by an adult relative or friend, to an undesignated floor of the institution.<sup>21</sup>

The patient becomes isolated from the world, from the people who take care of him/her and his/her emotional needs—his/her boss, his/her work, his/her wife or husband, his/her business-associates, his/her friends. When she/he enters the hospital, this world is left pretty much outside. Now, suddenly, the patient becomes the recipient of care; is being put in a position of passivity. Decisions are being made for him/her and she/he does not take part in it anymore.

In the hospital the patient is put in the situation of becoming an object, the object of examination, of treatment, of nursing. She/he lives in a network of related functions in which a large number of people deal with him/her: the specialist, the radiologist, the hospital analyst, the nursing staff, the social worker, the pastor. Yet she/he her/himself has virtually little or nothing to do in all this: she/he has to let her/himself be treated and is entirely dependent on decisions made about him/her by others. All this tends to make him/her feel uncertain. Where up to now she/he has been used to making his/her own decisions and acting on his/her own

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<sup>21</sup>Ester Lucile Brown, "Meeting Patient's Psychosocial Needs in the General Hospital," in James K. Skipper (ed.) Social Interaction and Patient Care (Philadelphia: Lippincott, 1965), p. 7.



initiative, she/he suddenly has to entrust him/herself to a number of people she/he does not know in an unfamiliar situation, and on these people depends the outcome of his/her illness, which is already filling him/her with anxiety.<sup>22</sup>

Hospitalization tends to provoke feelings of fear and panic, of vulnerability and helplessness. The patient wants to react; wants to and needs to express all these feelings, but they are negative and negative feelings may aggravate the people to whom they are directed, the doctor or nurse or other members of the team and after all, the patient is entirely dependent on them: on their goodwill!

Balint<sup>23</sup> found in his study that every doctor had a vague, but almost unshakably firm, idea of how a patient ought to behave when ill and what is a "good" or "bad" patient. Although this idea is everything but explicit and concrete it is immensely powerful and influences practically every detail of the doctor's work with his/her patients. It was almost as if every doctor had revealed knowledge of what was right and what was wrong for patients, to expect and to endure, and further, as if she/he had a sacred duty to convert to his/her faith all the ignorant and unbelieving among his/her patients.

Hospitalization tends to provoke depressive feelings in the patient. The patient becomes aware that she/he has lost the ability

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<sup>22</sup>Heije Faber, Pastoral Care in the Modern Hospital (Philadelphia: Westminster Press, 1971), p. 19.

<sup>23</sup>Michael Balint, The Doctor, His Patient and the Illness (London: Pitman Medical, 1974), p. 216.

to master his/her environment. She/he finds her/himself doing what she/he thinks others expect of her/him. She/he finds her/himself increasingly dependent on others for help in alleviating the pain and physical distress: She/he must discontinue accustomed activities, modify or give up longstanding habits. The abrupt changes in her/his role in life induce feelings of defeat, helplessness, fear, anxiety which could lead to abnormal patterns of behavior.<sup>24</sup>

It can sometimes appear that the role of patient has its attractions. One becomes recipient of care. There is time for relaxation in bed instead of bustle. There will be time to think, to meditate and to dream. All these things may and do occur for some people in their terminal illness, for example, the elderly person who considers that his/her life has been satisfying and is completed.<sup>25</sup>

### 7.3 Reaction to the Loss of Body-Image

Although the concept of loss is generally discussed in relation to dying and death, physicians, nurses, pastors, etc., must frequently attend to patients who have experienced many other kinds of significant loss, often ones related to the body, its parts and its functioning. Such losses include, among others, those involving the

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<sup>24</sup>"The Conspiracy of Silence in Cardiovascular Diseases," Geriatric Focus, V:1 (1966), 5.

<sup>25</sup>John Hinton, "The Psychology of Dying," in Norman Autton (ed.) From Fear to Faith (London: S.P.C.K., 1971), p. 37.

external bodily organs such as occur through limb amputation, mastectomy, and bodily disfiguration.

With modern advances in medical treatment and surgical techniques, amputation of body parts has become prevalent. A total of 35,000 limb amputations are performed in the United States annually, in addition to amputation of other external organs. Cancer of the breast accounts for almost 25% of all malignancies in women, the majority of which are treated by breast surgery in combination with other forms of treatment. Loss or disfiguration of external organs through other than surgical means occurs increasingly, particularly as a result of highway accidents. Such "partial loss" in relation to external organs of the body is an increasingly common experience, and may present complications for the patient, his/her family, and the medical team.<sup>26</sup>

Understanding some of the diverse reactions which may accompany change or loss of external organs can best be conveyed by reference to the concept of body-image, an important construct which in recent years has gained wide recognition in psychology, psychiatry and neurophysiology.<sup>27</sup>

Through the way our bodies are handled, treated and loved from early childhood by our parents, our families and by society at large

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<sup>26</sup>Bernard Schoenberg and Arthur Carr, "Loss of External Organs: Limb Amputation, Mastectomy, and Disfiguration," in Schoenberg, Loss and Grief, p. 120.

<sup>27</sup>Ibid., p. 121.

we develop an image, a picture of our bodies. This concept is an internalized amalgamation of the accumulated unconscious, preconscious and subconscious experience of the organism in its response to the life process.<sup>28</sup>

The patient's response to loss of a body part varies with the specific significance of that part to the patient. The emotional impact of a mastectomy, for example, has a significance to a woman that transcends functional or cosmetic factors, since a breast, like the uterus, is far more likely to symbolize a woman's femininity. Her reaction to losing a breast will therefore depend to a great extent on her feminine identity, which in turn is determined by her previous relationships with parents, other family members, and more currently, her relationship with her husband.<sup>29</sup>

In a counseling session a wife who had a mastectomy expressed herself in this way.

It was an experience beyond words. I felt degraded. I could not watch myself in the mirror. I could not stop crying . . . .

Her husband:

Every time when I reach out to her and I feel the big scar and the emptiness, the total emptiness where once there was a well formed breast. I pull my hand back in disgust. I become nauseated! Sick! When I look at her I feel sorry for her. She lost part of herself. She lost her womanhood . . . I cannot take it!

And a woman who was terminally ill with cancer:

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<sup>28</sup>Edgar N. Jackson, "Body Image and Grief Response," in Austin H. Kutscher (ed.) Religion and Bereavement (New York: Health Sciences, 1972), p. 137.

<sup>29</sup>Schoenberg and Carr, "Loss of External Organs . . . ," p. 123.

A nurse came with an electric razor to shave my head. This was a most humiliating experience and made me feel unfeminine and degraded.<sup>30</sup>

As with the loss of a limb, the loss of a breast will be experienced as the death of a body part and may symbolize or be psychologically comparable to the loss of a significant person. The reaction to the loss is grief persisting during a period of mourning for the lost breast and what it may symbolize. Depending on the emotional investment in the lost part the patient will suffer severe or less severe post-operative depressions, feeling helpless and ineffectual.

Sudden changes in the body-image, resulting from surgery or trauma will evoke great anxiety. The anxiety reaction is related to fear of rejection by significant figures because of the deformity, and because the abruptness of the alteration in body appearance has not yet permitted the formation of a new body-image.

The common feelings that accompany anxiety are shame, hostility, guilt, followed by emotional withdrawal and physical avoidance of others.

The impact of the loss of a body part through amputation or the "loss" of appearance through facial disfiguration depends greatly on feelings of the individual about her/himself. If she/he is secure in his/her feelings that she/he is loved for him/herself and not for

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<sup>30</sup> Sadie Dunnet, "I Know I Am Dying," Sunday Times Magazine (November 25, 1973)

his/her appearance, physical ability or his/her capacity to work, she/he is more capable of adjusting to the loss.<sup>31</sup>

#### 7.4 The Psychology and Needs of the Terminally Ill Adult

Psychologically, the dying differ little from other physically ill patients. They are, in spite of the closeness of death, still human beings with human emotions. Most people die as they have lived. In cases of long lingering illness where the body is sapped from its somatic strength the work of the ego, guardian of smooth functioning, is undermined. Then, usually the hostile become more hostile; the fearful more fearful, the weak, weaker.<sup>32</sup>

The literature on the dying patient is primarily concerned with the fear of death and whether or not to tell the patient that she/he is terminally ill.<sup>33</sup> There are many arguments for telling and just as many against telling.

In her studies with terminally ill patients in Chicago, Elizabeth Kübler-Ross found that only 1.5% of the patients interviewed denied the fact of their impending death.<sup>34</sup> Cartwright and Anderson's

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<sup>31</sup>Schoenberg and Carr, "Loss of External Organs . . . ," p. 123ff.

<sup>32</sup>Daniel Cappon, "The Psychology of Dying," Pastoral Psychology, XII (February 1961), 36.

<sup>33</sup>C. Aldrich and M. Knight, "The Dying Patient's Grief," Journal of American Medical Association, CLXXXIV:5 (1963), 329.

<sup>34</sup>Elizabeth Kübler-Ross, On Death and Dying (New York: Macmillan, 1969)

survey in Britain noted that according to their informants seen not long after the death of the patient, more than 50% knew that they were terminally ill.<sup>35</sup> Cicely Saunders<sup>36</sup> writes:

In my own experience I find that the truth dawn gradually on many, even most, of the dying, even when they do not ask and are not told. They accept it quietly and often gratefully but some may not wish to discuss it and we must respect their reticence.

Patients may well reject early suspicions that they are terminally ill, because they may not be prepared to entertain such thoughts. They may be unprepared in more than one sense, being both unwilling and also unready to receive the knowledge. Many of the patient's clues come, not from the illness, but from other people (usually the family and members of the team) who know or suspect the diagnosis or even from the nature of the treatment administered.<sup>37</sup> The easier the communication that exists with the terminally ill patient, the greater the proportion who acknowledge that they may not have long to live. More than half the people who are in hospitals during their terminal illness are prepared to indicate or talk forthrightly—given a chance—about their views that the outcome may be a fatal one. Four out of five patients say they would like to be told that they are terminally ill. If a patient has recognized in her/himself that she/he may be dying and wants to speak a little more realistically

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<sup>35</sup> Ann Cartwright et al., Life Before Death (London: Routledge and Kegan Paul, 1973)

<sup>36</sup> Cicely Saunders, Care of the Dying (London: Macmillan, 1959)

<sup>37</sup> Hinton, "The Psychology of Dying," p. 39.

about this, she/he can feel very isolated if no one is willing to listen.<sup>38</sup>

Most terminally ill patients may keep themselves busy with constructing a "puzzle of their lives,"<sup>39</sup> i.e., putting the pieces of their lives together. During this process she/he may experience various needs and emotions.

They may feel the need to talk about their past, their parents, childhood, marriage. They may want to talk about decisions they had to make, their work, old friends and colleagues, their children, their illness, the first symptoms, their fear and anxiety, their religion and trust and hope. Whether this puzzle is built with preciseness and care or in great hurry will depend upon the physical and emotional strength of the patient and the time available to the patient. Often the information received from a patient in this way, even though it may only be a few sentences may serve as a stepping stone in building a relationship with the family because it is so characteristic of the patient.

In working on this "puzzle" or a picture of him/herself the patient is looking for harmony—This is how it was: This is where I am now. Life is seen as a totality. In the process unfinished business is often dealt with. Completing the puzzle and seeing life in perspective may bring a feeling of serenity and fulfillment.

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<sup>38</sup>Ibid., pp. 40-42.

<sup>39</sup>Willem Berger, De Laaste Levensfase (Bilthoven: Amboboeken, 1973), III, 37f.



#### 7.4.1 The Patient's Fear

Pain and fear are closely related—pain is a reaction to damage while fear is the anticipation of pain and damage. The patient who experiences pain may be regarded as fearful in the sense that she/he expects more pain or cannot anticipate the alleviation of pain. Emotional or feeling states such as fear and depression are also painful and contribute to the experience of pain, regardless the degree of physical damage.<sup>40</sup>

For many people the thought of death and dying are fearful. In our day, and in our society, death has become associated in our minds with so many frightening things. Death may carry with it connotations of destruction, ruin, anarchy, chaos, loss of control, grief, suffering and punishment. It is true that dying can be a time of anxiety, but given a reasonable standard of care, fear does not predominate, in the way that many anticipate.<sup>41</sup> Fortunately, most dying persons seem to have little fear of death per se. What many fear is that their dying might be a long-drawn-out, messy or painful business.<sup>42</sup>

The terminally ill patient may experience exaggerated fear of dying. This magnified fear may be the result of displacement from

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<sup>40</sup>Schoenberg and Senescu, "The Patients Reaction . . . , p.223.

<sup>41</sup>Hinton, "The Psychology of Dying," p. 43.

<sup>42</sup>Alvarez, "Care of the Dying," p. 87.

other sources of anxiety, such as a fear of the unknown, separation, abandonment, loneliness, mutilation, loss of control, loss of identity, and infantile behavior.<sup>43</sup>

One may say that the fearful patient imagines dangers which then elicit more fears. Many patients regard fear as an indication of weakness, inferiority, or immaturity and therefore are reluctant to express it.<sup>44</sup> The unpleasant mood people experience is likely to be sadness, rather than fear. If people recognize that they are dying and do not really wish to die yet, then there is sorrow and depression.<sup>45</sup>

#### 7.4.2 The Patient's Grief

Grief is the necessary total process, emotional, spiritual and physical, in which the individual terminates his relationship with an important person or thing in order to reinvest his life in other persons or things. And grief is a "necessary" process, for without it, the old relationship cannot be adequately ended and other relationships will always suffer from emotional deprivation. From the moment a person learns he/she is facing death, he/she begins to grieve. All the feelings that are vital elements in the grief process

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<sup>43</sup>E. Mansell Pattison, "Afraid to Die," Pastoral Psychology, XXIII:225 (June 1972), 41ff.

<sup>44</sup>Schoenberg and Senescu, "The Patient's Reaction . . . ," p. 224.

<sup>45</sup>Hinton, "The Psychology of Dying," p. 43.

may come into play: shock, disbelief, denial, anger. Her/his grieving may be about what is, what may be, or what might have been. Her/his grief has a very personal nature. The grieving is for her/his pain, her/his losses; her/his past being, and what her/his future might have been.<sup>46</sup> The terminally ill patient may feel frightened to express her/his anger towards a member of the team because of her/his dependent position. To control or hide anger, the patient may withdraw from all self-assertive behavior and become emotionally inaccessible. She/he may experience a feeling of great relief when her/his anger is acknowledged and she/he discovers that she/he will not be punished. The patient who is allowed to discuss her/his angry feelings is far less likely to regard the environment as hostile and to develop feelings of guilt and depression.<sup>47</sup>

The terminally ill patient involuntarily begins the process of letting go of the world and those whom he has loved and who have loved him. If the grief process is successful, the dying patient arrives at the moment of death with a peace born of an emotional detachment from the concerns of life. She/he is, in a sense, ready to die. If the grief process is thwarted, the act of dying may be painful and tormented indeed.<sup>48</sup>

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<sup>46</sup>Melvin J. Krant, "The Dying Patient—Medicine's Responsibility," Journal of Thanatology, I:1 (January-February 1971), 49.

<sup>47</sup>Schoenberg and Senescu, "The Patient's Reaction . . . ," p. 227.

<sup>48</sup>Robert Buxbaum, "Grief Begins Not with Death, But Knowing It is Near," Texas Medicine, LXII:44-5 (October 1966), 44.

### 7.4.3 The Patient's Guilt

An integral part of guilt is the fear of punishment based on the child's belief that the all-powerful parent sees, hears, and knows all. The guilty individual may feel bad, dirty, and unworthy and may anticipate punishment, the consequence of which is anxiety and the reduction of her/his self-esteem. The patient may feel guilt over hostile thoughts and feelings as well as overtly angry behavior. An ill patient may view her/his disease as a punishment visited upon her/him for past sins or indiscretions—"If I hadn't been bad, this wouldn't have happened to me." or "What have I done to deserve this?"<sup>49</sup>

A terminally ill patient wrote:

At an intellectual level I could tell myself that I had some guilt feelings about my family, particularly about my children, and not deal with it very much beyond a kind of superficial recognition that it wasn't the illness or dying itself that was really bothering me, but something more related to my relationship with my family and my feelings of not really having been as good a father as I should have been.<sup>50</sup>

Existential guilt in the patient is perhaps more difficult to deal with. It consists of an awareness in one's own eyes of incompleteness, of failure to realize one's potential and of falling short of goals. These feelings, which are perhaps more common in individuals who

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<sup>49</sup>Schoenberg and Senescu, "The Patient's Reaction . . . ," p. 228.

<sup>50</sup>"Notes of a Dying Professor," Pennsylvania Gazette (March 1972), 23.

suffer from fatal illness in young or middle adulthood, cause a crisis of identity. They are a consequence of the business of living in a responsible way without self-deceit.<sup>51</sup>

#### 7.4.4 The Patient's Pleasure

It is understandable that the terminally ill patient will be preoccupied with her/his illness and with working through all the different emotions occupying her/his heart and her/his mind. She/he may isolate her/himself physically and emotionally from society, family and friends. She/he may show little interest in gaining any pleasure from life's activities and other sources.

This is especially important during this time because pleasure can be viewed as having a "buff-effect," neutralizing the inevitable pains and frustrations which accompany loss of health and function. This deprivation of pleasure contributes to the development of a vicious circle of which pain, anger, guilt and depression are constant components. The family and the hospital very often lack creativity in offering the patient a "surprise" which could lead the patient to experience pleasure and to forget her/himself for a little while. Many patients, although terminally ill demonstrate the need for something special and pleasurable which can break the monotony and the anxiety of waiting to finally say goodbye and to die.<sup>52</sup> Many

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<sup>51</sup>Verwoerd, Communication with the Fatally Ill, pp. 150-151.

<sup>52</sup>Schoenberg and Senescu, "The Patient's Reaction . . . ," pp. 229-230.

patients are really looking for guidance, perhaps permission from the staff and the family to get involved in pleasurable activity; to do and to enjoy even though death may be very close, without risking being rejected by the team, the family and society. I remember a man at St. Christopher's in London, who daily went to the pub round the corner where he had his favorite beer and visited with friends until a day or two before his death!

About three weeks before Christmas, 1974, a shopping center in the suburbs of London closed its doors to the general public one evening at 5 pm. Terminally ill patients from St. Christopher's were taken there by ambulance, taxi and private cars. They had the whole shopping center to themselves and without the fear of being in another person's way or being pushed over by the pre-Christmas shopping crowds, they could buy their "last" presents for loved ones. It was a most successful evening and they all returned to St. Christopher's physically tired, but emotionally lifted and very happy.

#### 7.4.5 The Five "Stages" of Elizabeth Kübler-Ross

Throughout her book, On Death and Dying<sup>53</sup> Elizabeth Kübler-Ross gives a clear impression that the terminally ill patient goes through five different emotional stages in the process of working through her/his feelings: 1. Denial and isolation, 2. Anger, 3. Bargaining, 4. Depression with a great sense of loss, 5. Acceptance.

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<sup>53</sup> Kübler-Ross, On Death and Dying.

The stages overlap, but do not replace each other. Hope usually persists through all the stages and is maintained up to the end.

If a patient has had enough time (i.e., not a sudden, unexpected death) and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his "fate" (Acceptance).<sup>54</sup>

The process is very clearly a linear process.

Most of the students (students in Clinical Pastoral Education and in Nursing) with whom I had contact during the past five years had the distinct impression, after they had studied On Death and Dying, that the process was linear, the patient moving from one stage into the other. Every terminally ill patient visited by them was categorized and placed into one of the stages. I found this to be disastrous in many cases, blocking communication totally.

In "Questions and Answers on Death and Dying"<sup>55</sup> Elizabeth Kübler-Ross tries to correct this impression when she says:

I hope that I am making it clear that patients do not necessarily follow a classical pattern from the stage of denial to the stage of acceptance. Most of the patients have exhibited two or three stages simultaneously and those do not always occur in the same order.<sup>56</sup>

She feels that if a person has reached the stage of acceptance and begins to regress to an earlier stage, it is usually a sign of the team's inappropriate handling of the patient! She says that the

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<sup>54</sup>Ibid., p. 112.

<sup>55</sup>Elizabeth Kübler-Ross, Questions and Answers on Death and Dying (New York: Collier, 1974).

<sup>56</sup>Ibid., pp. 23-24.

patient does not necessarily have to go through all five stages in order to die with peace and dignity.

But then she says that the family and staff usually limps behind in the stages and that the family has to go through all the stages a second time after the death in order to complete the process of bereavement.<sup>57</sup> I find that she contradicts herself in saying this and that she reverts to her position in On Death and Dying.

I find her stage-system too neat. "Now, I'm at the anger stage, next comes bargaining." The stages are general enough so they could apply to every case in some way or another.<sup>58</sup>

In my experience with terminally ill patients I have found that patients vary as greatly as emotions and feelings vary. There is really no structure. Every person must do her/his own dying and she/he does it in a very special and unique way, related to the very special human being each one is! Each one asking to be accepted for what she/he is!

#### 7.4.6 Faith Healing

I do not intend to discuss healing in answer to prayer (often termed faith healing) in a comprehensive manner. However, I want to point out that the pastor working in a modern hospital and the parish minister may be confronted by members of the medical team, students

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<sup>57</sup> Ibid., p. 96.

<sup>58</sup> Warren Shibbes, Death (Whitewater, WI: Language Press, 1974), pp. 222-225.



and parishioners with questions and facts concerning this important matter. Especially cancer patients and their families are often emotionally, spiritually and even financially exploited by members of different religious sects who offer "complete cure through faith and prayer." It is important that the pastor read in this area and decide for him/herself how she/he understands and interprets these occurrences theologically, psychologically and pastorally.

Miracles of healing are recorded in several places in the New Testament. In some of them faith was regarded as a prerequisite,<sup>59</sup> in others, there is no mention of faith.<sup>60</sup> In the cases where faith was mentioned—was this faith psychological or theological?<sup>61</sup> Psychological faith means simply trust or confidence in the person of the healer, Jesus of Nazareth; theological faith means a positive relationship to God through Jesus.

Von Rad<sup>62</sup> says that faith involves humankind, but it is dependent upon God. In Hebrew "to have faith" means "to make oneself secure in Jahweh."

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<sup>59</sup> Luc. 8:48; Matt. 15:28.

<sup>60</sup> Luc. 6:10; 7:14-15; 17:13-14.

<sup>61</sup> Eldon R. Hay, "What is the Nature of 'Faith' in Healing?", Perkins Journal (Spring 1973), 17.

<sup>62</sup> Gerhard Von Rad, Old Testament Theology (New York: Harper & Row, 1962), I, 171.

For Bornkamm<sup>63</sup> genuine faith (in connection with a healing)

has the following elements:

1. all human possibilities have been exhausted
2. the counting on the power of Jesus which knows no bounds—or in other words, the linking of faith with power and miracle;
3. Faith as very definitely counting on and trusting God's power—not in any general sense, but in a very concrete sense.<sup>64</sup>

Faith becomes real where strength and weakness meet. It is the opposite of all doubt (Mk. 11:22f). That is why Jesus in the story of the epileptic boy rejects that very modest word of the father, so understandable after all his earlier experiences: "If you can do anything," and ascribes to faith a power which knows no bounds: "All things are possible to him who believes (Mk. 9:22f). Does he demand too much of the petitioner and thus deprive him of his help? Not at all. Yet the further conversation with the father shows the only form his faith can take. "And the father of the child cried out: 'I believe; help my unbelief!'" (Mk. 9:24). I believe!—here the petitioner has indeed exceeded his own ability, and confesses a faith greater than he really has. Help my unbelief—here he who falls short of faith throws himself on the power and help of Jesus. In this paradox of faith and unbelief, as the story points out, faith becomes true and capable of receiving the miracle of God. Where Jesus does not find this faith, he cannot work a miracle (Mk. 6:1-6).

Miraculous healings continued throughout the history of the Christian church until today. Luther who had denied the gift of healing for his time, lived to see his friend Melanchthon visibly brought from the point of death through his own prayers. Five years later in 1545, the year before he died, when asked what to do for a man who was mentally ill, Luther wrote instructions for a healing

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<sup>63</sup>Gunter Bornkamm, Jesus of Nazareth (New York: Harper & Row, 1960), pp. 130-131.

<sup>64</sup>Hay, "What is the Nature of 'Faith' in Healing?", p. 20.

service based on the New Testament letter of James, adding, "This is what we do, and that we have been accustomed to do, for a cabinet-maker here was similarly afflicted with madness, and we cured him by prayer in Christ's name." Like the two great giants of the church before him, Augustine and Aquinas, both—he seems to have learned in his mellow years to value, rather than to disregard, this gift from God.<sup>65</sup>

The Bible implies that healing, at every level and with no particular distinction among the levels, is good from God's point of view. Function restored is God's will, whether the previously lost function be ability to walk or, as in the case of the Gadarene, ability to communicate with his fellows. God is for, with, and in all healing processes, at any level whatsoever. In the modern situation, God is equally present in the surgeon's tools, the psychiatrist's conversations, the internist's nutritional prescriptions (if accurate), and the pastor's prayer. God is for healing, in the sense that restoration of function, with necessary supporting structures, is always opted for.<sup>66</sup>

I believe that healing can and does take place in answer of faithful prayer, subject to the sovereign will of God. In the miracle of healing one can see God at work.

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<sup>65</sup>Morton T. Kelsey, Healing and Christianity (New York: Harper & Row, 1973), p. 233.

<sup>66</sup>Seward Hiltner, "The Bible Speaks to the Health of Man" (Paper read at the National Methodist Convocation on Medicine and Theology, Rochester, Minnesota, April 6, 1967).

### 7.5 Pastoral Care of the Terminally Ill Adult

I am a student nurse. I am dying . . . I know you feel insecure, don't know what to say, don't know what to do. But please believe me, if you care, you can't go wrong. Just admit that you care. That is really for what we search. We may ask for why's and wherefore's, but we don't really expect answers. Don't run away—wait—all I want to know is that there will be someone to hold my hand when I need it. I am afraid. Death may get to be a routine to you, but it is new to me. You may not see me as unique, but I've never died before. To me, once is pretty unique.

You whisper about my youth, but when one is dying, is he really so young anymore? I have lots I wish we could talk about. It really would not take much more of your time because you are in here quite a bit anyway.

If only we could be honest, both admit of our fears, touch one another. If you really care, would you lose so much of your valuable professionalism if you even cried with me? Just person to person? Then, it might not be so hard to die—in a hospital—with friends close by.<sup>67</sup>

Pastors give a variety of reasons for their ignoring the terminally ill adult in their ministry and pastoral care. One of the most frequent heard is also one stated by Norman Autton,<sup>68</sup> "Communication will often be difficult with the dying patient, for there may be inability to speak distinctly or think clearly."

Sieber<sup>69</sup> reports on a study done at the Clinic of the University of Erlangen-Neurenberg, in Germany. It was found that 66.4% of the patients were fully conscious during the last 24 hours before

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<sup>67</sup>"Death in the First Person," American Journal of Nursing (February 1970)

<sup>68</sup>Norman Autton, Pastoral Care in Hospitals (London: S.P.C.K., 1968), p. 45.

<sup>69</sup>Georg Sieber, Ouder Worden (Nijkerk: Callenbach, 1972), p. 121.

their death. Only 1.8% of the patients showed indications that they were not aware of the fact that death was closing in and only 1.8% of the patients gave indications of the presence of a fear of death. The majority of the patients had no physical pain during the last hours.

With the development of modern medicine pain and discomfort can be controlled which enable the patient to remain alert and able to communicate, in many cases, until the very end. It has been my experience that the majority of patients enter the last stages of their life with serenity and dignity. When it is recognized, either openly or tacitly, by the patient that she/he does not have long to live, it does not mean that the remaining part of life is not important. If illness has not blurred the quality of life too much the last phase of life in this world can be, with the help of the team and the family, very precious. People can and do accept with dignity that they are dying. It tends to come more easily to those who have completed their expected life span.<sup>70</sup>

Without exception, studies indicate that communication between the terminally ill and both staff and relatives is poor. According to Crane<sup>71</sup> this may be explained by the fact that interaction with persons who have no future is frustrating in our culture. The basic

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<sup>70</sup>Hinton, "The Psychology of Death," pp. 44-45.

<sup>71</sup>Diana Crane, "Dying and Its Dilemmas as a Field of Research," in Orville G. Brim et al., The Dying Patient (New York: Russel Sage Foundation, 1970), p. 313.

issue of communicating with the patient who is terminally ill would seem to be, "How to help the patient, even though very ill and dying to be an individual human being?"

Illness per se does not change the person. The fact that "people" have become "patients" does not alter the fact that they remain "people," each of them an individual with differing backgrounds, differing ways of reacting to what happens to him or her; she/he does not become "the occupant of the bed at the window." She/he remains an individual in her/his own right. The feeling of being accepted and considered worthy is one of the most potent forces of building inner strength and equips one to deal with life's difficulties.<sup>72</sup> Totally unacceptable is the remark we hear so often in our ultra modern technological hospitals: "There is nothing more we can do for the patient." There may be no further surgery or treatment or drug therapy. There still remains relationship, caring, the comfort of the presence of a loved and a trusted one.<sup>73</sup> It is important that the patient is helped to really live until she/he dies!<sup>74</sup>

Cicely Saunders says:<sup>75</sup>

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<sup>72</sup>Minna Field, Patients Are People (New York: Columbia University Press, 1967), pp. 140ff.

<sup>73</sup>Barbara McNulty, "Care of the Dying," Nursing Times (November 30, 1972)

<sup>74</sup>Peter Hofstede, Tot Onze Diepe Droefheid (Baarn: Bosch en Keuning, 1970), p. 155.

<sup>75</sup>Cicely Saunders, "The Management of Fatal Illness in Childhood," Proceedings of the Royal Society of Medicine, LXV:6 (June 1969), 550-553.

To accept the existence of purely terminal care never means that we say, 'There is nothing more to be done,' but always that we can say truly that 'everything possible is being done.' The right kind of confidence comes from efficiency. Much can be done to control pain, nausea and vomiting, to relieve dyspnoea and confusion, both so frightening to any patient. Skill at this stage helps us to come to a patient with ever renewed interest and that positive feeling which is transferred without words. It can do so much to lift the feeling of helplessness from a patient as well as from ourselves.

In the modern hospital patients and family are looking, more than ever before, for a person who demonstrates confidence in the medical-technical-labyrinth, and yet, willing to take a place next to them as a fellow human being, willing to accompany them on their road during this time of crisis, willing to search and to struggle with them.<sup>76</sup>

The question then, it seems to me, is where to get such a person? I believe that the pastor is in a unique position<sup>77</sup> to accept this task and responsibility and complete it successfully.

Pastors complain that they are usually hurriedly sent for when it is too late to give the patient the spiritual comfort because the patient is comatose or already dead. Why is it that the pastor is called at such a late stage when the patient has already lost consciousness?<sup>78</sup> It is my contention that the pastor need not be "called" at all. She/he should fill her/his place in the team with

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<sup>76</sup>L.L. Th. Brands, In De Schaduw Van De Dood (Hilversum: Gooi En Sticht, 1974), p. 130.

<sup>77</sup>See Chapter 6.3.

<sup>78</sup>Ernestie Weterings, "Omgaan Met Stervenden," in F.J.R. Huygen et al., Menswaardig Sterven (Bilthoven: Amboboeken, 1974), p. 176.

the necessary involvement and competence. It is entirely up to the pastor to keep up to date with the terminally ill patients under her/his care. She/he should determine the patient's physical and emotional needs in close co-operation with the other members of the team and respond to these needs to the best of her/his ability. This also includes being present and available during the final hours. But it must be more than a responsibility or a job. By being present the pastor will meet some of her/his own needs. It will add to the completion of the process of grief for a patient who became a precious human being, loved and respected. Having visited a terminally ill patient over a period of time the pastor, who is only a human being (Thank God for that!) will experience an emotional investment in the patient. If the pastor is not kind to her/himself and creates opportunities which may assist in finishing her/his unfinished business with the patient she/he will experience (unconscious) resistance to entering into another relationship with another terminally ill patient. I would like to refer to what I have said about a support group for the pastor<sup>79</sup> and emphasize its importance once again.

Carol Wise<sup>80</sup> defined pastoral care as "the art of communicating the inner meaning of the Gospel to persons at the point of

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<sup>79</sup>See Chapter 6.3.

<sup>80</sup>Carol A. Wise, The Meaning of Pastoral Care (New York: Harper & Row, 1966), p. 8.



their need." According to Heije Faber<sup>81</sup> the task of the pastor in the modern hospital is to help the sick maintain a sense of belonging to the community in a boundary situation, to assist the patient in coping with his illness in faith, to encourage the patient to learn to live at a deeper level.

Everyone who assumes professional responsibility for the terminally ill patient and her/his family should be fully knowledgeable about attitudes toward death, cultural mores and spiritual beliefs concerning death and the dynamic interaction between family members when confronted with terminal illness.<sup>82</sup> An understanding of the patient's needs to accommodate to dying is necessary, as is an understanding of the psychological positions of denial, bargaining, depression and grieving before death. Through an understanding of these problems, the pastor may work to dispel the anxiety of loneliness, isolation and hostility.<sup>83</sup> If we are to care for the terminally ill patient adequately we need to be part of and party to as much as possible of her/his life. If we only meet a patient on the ward, apart from her/his family we can only judge her/him, assess her/him in the context of the ward and how she/he

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<sup>81</sup>Faber, Pastoral Care in the Modern Hospital, p. 49.

<sup>82</sup>Elizabeth R. Prichard, "Planning For the Terminally Ill Patient: The Social Worker's Responsibility," in Ivan K. Goldberg (ed.) Psychopharmacologic Agents For the Terminally Ill and Bereaved (New York: Columbia University Press, 1972), pp. 41-42.

<sup>83</sup>Krant and Sheldon, "The Dying Patient . . . ," p. 15.

relates to the ward environment. If we consult only with relatives in the sister's office, away from the patient, we are in danger of isolating the patient, or making her/him feel the object of our discussion, rather than the subject. We are always in danger of helping to erect a wall of non-communication between the patient and her/his family and the pastor as a member of the team, should avoid it at all cost.<sup>84</sup>

Pastoral care demands an acutely sensitive "ear" and an understanding of the needs of this individual (who happens to be terminally ill) in this situation at this time. The pastor must be prepared not to fall back on traditional forms (Scripture reading and prayer), but simply to be with the patient, to show her/his solidarity with the person in her/his illness. One patient described the pastor as "the man of God." Perhaps we may say the pastor is a symbolic figure, a person who represents God, makes God present for the patient in her/his unique situation. The pastor becomes an ally. She/he is seldom asked for theoretical discussions about God. Far more important is her/his attitude about life, the way she/he lives and loves, indicating the relevance of God in her/his life. The pastor is asked for faith, which is revealed in the way she/he communicates with the patient and the family, sharing in their anxieties and struggles, being open to the personal history, the family and

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<sup>84</sup>B.J. McNulty, "Meeting the Problem of Communication in the Ward and in the Home," in Graham Bennette (ed.) Cancer Priorities (London: George and Chase, 1971), p. 65.

friends, enemies, the pain, the loss and her/his God.<sup>85</sup>

The time for evangelism and exhortation is not at the death bed. The failing physical strength of the patient may never be used to exploit her/him; to convert her/him to a new belief or religion. On the other hand, the deeply religious and even the intellectually curious agnostic, may desire and require the presence of a sensitive, informed, clinically trained theologian at her/his bedside when the end draws near. Dying patients cannot benefit from the presence of an emotionally excited, evangelistic minister.<sup>86</sup>

It has been my experience that the majority of terminally ill people, still mentally alert, ask questions about the meaning of life and the meaning of death. They do not only appreciate the presence of a sensitive pastor, but they ask for her/him. Mrs. K.: "I am Jewish; I have never been a practicing Jew but now that I know I am going to die religion suddenly becomes important to me. I want to know more about religion and faith and hope." Mrs. H.:

I used to go to church only for weddings and funerals. But since I became terminally ill my faith has grown a lot. Now I find prayers helpful and meaningful. I would like the pastor to visit me more often. I do a lot of praying on my own. I feel comforted. I take every day just as it comes and it will all right itself one day.

Mrs. F.: "I want to talk to you concerning life after death. I'm

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<sup>85</sup>Brands, In De Schaduw van de Dood, pp. 127ff.

<sup>86</sup>J.W. Annis, "The Dying Patient," Psychosomatics X:5 (1969), 290.

afraid I'm a big sinner. I have not paid enough attention to spiritual things during my lifetime."

Many terminally ill and lonely patients come to love the pastor who sees through them and their blustering and who likes the sweet, frightened, and very lonely being that lives inside the ailing body. They come to appreciate and love the visits and friendship of a pastor who has time and empathy.<sup>87</sup> It is important that the discussions should be patient-centered and without the pastor trying to interject his philosophy into the structure the patient is building. A person is likely to feel more at ease when she/he is allowed to explore the meaning that death and her/his own dying has for her/him and eventually arrive at her/his own philosophy and acceptance.<sup>88</sup>

According to Bowers et al.,<sup>89</sup> many clergy wear masks to protect themselves from the full person-to-person encounter. Only as the wearer can be aware of her/his masks and tear them off can there be a free and open communication with the patient.

1. The mask of set-apartness: The act of ordination marks a man as a custodian of the sacred mysteries, as if she/he knows more of the truth than others, and is granted powers that are reserved for

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<sup>87</sup>Alvarez, "Care of the Dying."

<sup>88</sup>Joan M. Baker and K.C. Sorensen, "A Patient's Concern With Death," American Journal of Nursing, LXIII:7 (July 1963)

<sup>89</sup>Margaretta K. Bowers et al., Counseling the Dying (New York: Nelson, 1964), pp. 67-68.

those of special goodness.

2. The mask of ritualized action: The use of formalized prayers and traditional procedures makes it possible to enter into a human relationship protected against the full encounter with the person, because the communication is general rather than specific.

3. The mask of special language: Phrases like "Saving grace" and "redemptive power" may have a familiar ring associated with acts of public worship, but they may mean little and say nothing to the patient, for the deeper substance of the words has never been fully employed. They may mean something to the pastor, or they may be comfortable phrases that can be said with assurance that their deeper meaning will not be called into question.

4. The mask of special attire: The special clothing that members of the clergy traditionally wear may afford ease of access in the hospital, but they say, "I am different from you," at the moment when it is important to say, "In this moment I share with you the thoughts and feelings that penetrate your aloneness."

5. The mask of busyness: Some pastors carefully cultivate the idea that they are terribly busy about a number of important tasks and that they break in upon these many duties to pay the dying patient a quick favor by their short visit.

The pastor should draw up a chair and sit down next to the bed of a terminally ill patient. Now pastor and patient are on equal level—meeting each other eye to eye. Two human beings trying to cope with problems, instead of the pastor being the professional, towering over patient and taking control. This action demonstrates

the pastor's concern, availability and sensitivity to the needs of the patient. The pastor must have a fine appreciation of timing and be sensitive to verbal and non-verbal cues.<sup>90</sup>

A salient problem for the patient is her/his realistic feelings of loneliness and isolation related to the mutual disengagement or withdrawal from others in her/his environment. Family, friends and even members of the team may have already begun to protect themselves against the painful feelings of guilt, failure, helplessness, anger, or grief by withdrawing from the relationship through varying degrees of emotional inaccessibility or physical avoidance. The primary need of the patient is to alleviate her/his loneliness and isolation by sharing her/his feelings with another person who can maintain neutrality and offer support and comfort. The pastor's primary goal is to assist the patient by enabling him/her to live at his/her highest level of functioning in all spheres of behavior, so that she/he may maintain gratifying relationships, continue activities, and approach death with a positive self-image.<sup>91</sup> It is important to evaluate the patient's ego strength at this stage. The pastor can do it in many ways: by her/his own personal impression of the patient from their contacts with one another, by the degree of success the patient has shown in past handling of stress,

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<sup>90</sup>Jeanne Benoliel, "Talking to Patients About Death," Nursing Forum, IX:3 (1970)

<sup>91</sup>Bernard Schoenberg, "Management of the Dying Patient," in his Loss and Grief, p. 249.

by the presence or absence of psychiatric or psychosomatic illness in the patient's history, and by the effectiveness of the patient's marital, social and occupational relations.<sup>92</sup> The parish minister will be in an excellent opportunity to evaluate the patient because of her/his knowledge of the patient as her/his parishioner. The hospital chaplain's position may be more complicated. She/he may see the patient in this critical situation for the first time in her/his life with no background information. In a situation like that the chaplain will have to deal with the here and the now situation using her/his own expertise and clinical intuition.

It may be helpful to find out what is important in the patient's life. What are her/his ambitions, values and religious convictions? Careful consideration of the spiritual dimensions of the patient's life can help the pastor proceed in the difficult task of communication with greater sureness and sensitivity because the depth and individual quality of the patient's personal convictions, as they have evolved from her/his particular religious affiliation, are likely to be influential in determining her/his ability to withstand stress. One's approach should not, of course, be guided by this factor alone, for the patient with deep spiritual convictions may be quite as susceptible to shock and trauma as the patient without

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<sup>92</sup>Verwoerdt, Communication with the Fatally Ill, p. 15.

them, when other factors so dispose her/him.<sup>93,94,95</sup> All these avenues can be explored. In searching for strengths in a patient, a useful principle is that people die pretty much as they live. Thus, if they had not been too thoughtful during their lifetime, they may not be very reflective at the time of their death. However, those philosophically inclined often would desire to discuss rather thoroughly the implications of their death and dying.<sup>96</sup>

The pitfall is that the pastor may prematurely disengage her/himself from the patient, as others in the environment have done, thus adding further to the patient's feelings of isolation. Therapy should focus on the patient's ability to live deeply and meaningfully in spite of the distressing circumstances. Emphasis should be placed on renewing emotional participation in life.<sup>97</sup> The patient's attitude towards her/his illness is of paramount importance for any therapy.<sup>98</sup> Therapy should not raise false hopes. The emphasis should be on the expansion and freeing of the self rather than on the possibility of

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<sup>93</sup>Ibid., p. 15.

<sup>94</sup>Richard Cabot and Russel L. Dicks, The Art of Ministering to the Sick (New York: Macmillan, 1963), p. 302.

<sup>95</sup>Carl G. Carlozzi, Death and Contemporary Man (Grand Rapids: Eerdmans, 1968), p. 35.

<sup>96</sup>Vincent Hunt, "Facing Death With the Patient—An Ongoing Contract," in David W. Berg and George G. Daugherty, The Individual, Society and Death (1972)

<sup>97</sup>Schoenberg, "Management of the Dying Patient," p. 250.

<sup>98</sup>Balint, The Doctor, His Patient and the Illness, p. 242.



physical recovery. Basic is an insistence on a real encounter—genuine contact between patient and pastor. Many times one has to be in full contact with a patient before she/he has the courage to accept being in contact with her/himself and with life. Contrary to the belief of many, the approach of death seems to give a much greater ego strength to the patient and the likelihood of a psychotic break is greatly lessened if the pastor therapist and the patient are in active encounter and both are clear about their goals.<sup>99</sup> The importance of good communication cannot be overemphasized. Bad communication causes suffering.<sup>100</sup>

According to Verwoerd<sup>101</sup> communication techniques in the management of the terminally ill patient are directed toward therapeutic goals on three levels: 1. the illness per se and its physical symptoms; 2. the patient's awareness of and psychological reactions to her/his disease and impending death and 3. the interpersonal vicissitudes in the illness situation.

Terminally ill people gain help when someone simply pays attention to their complaints, even if they have described them several times before. Telling itself brings ease and what is told will often indicate untried ways of bringing comfort. What is told

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<sup>99</sup>Bowers, Counseling the Dying, p. 90.

<sup>100</sup>R.G. Twycross, "A Plea For Eu Thanatos" (Unpublished Paper, London: St. Christopher's Hospice, 1973), p. 8.

<sup>101</sup>Verwoerd, Communication with the Fatally Ill, p. 28.

should be accepted at face value.<sup>102</sup> It is an art to listen to a patient, to use their language and allow them to keep their defenses if necessary. It takes just a little experience and the will to sit down and listen. If we do not understand what the patient is trying to communicate we can acknowledge that too and the patient will generally try to rephrase it if he senses that we really try to understand her/him. The pastor must listen to anything, listen to complaints about God, or the church or life in general, but just listen in a very accepting, caring, understanding manner. If the pastor can accept the patient the way she/he is, with denial, anger, bargaining, depression, then the patient will be able to work through her/his unfinished business and reach a stage of acceptance, enabling her/him to die in peace and dignity.<sup>103</sup>

Just sitting quietly with the patient for a while—being silent together—can be important. This shows the patient that one makes no demands on her/him. She/he does not have to speak if she/he can't manage it or doesn't feel like it. By staying with the patient and devoting time to her/him instead of looking for an excuse to hurry to another duty, one indicates that one can stand the patient's agonizing situation and that one is willing to share the pain. In certain difficult situations it gives, therefore, security and relief if the pastor sits quietly and silently with the patient. The fact

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<sup>102</sup>Hinton, Dying, pp. 116-118.

<sup>103</sup>Elizabeth Kübler-Ross, "The Dying Patient's Point of View," in Brim, The Dying Patient, pp. 167ff.

that the pastor can be silent with the patient is a confirmation of the quality of the relationship.<sup>104</sup>

The pastor must be aware of the importance of nonverbal communication. One conveys a message by the way one comes into the sickroom, by one's gestures, by one's eye contact, by a frown, or a sigh or a puzzled look. Nonverbal communication can be learned and/or improved by small-group experience of the "encounter" variety. This can increase the skills of the pastor.<sup>105</sup>

Touching is one of the most important forms of communication. The dying are in a certain sense the "untouchables" of our time. Remembering to shake a hand (carefully), hold a hand, touch an arm, a hand on the shoulder, all these have great potential for comforting a person who is dying. There are people who have an aversion in being touched. I remember Mrs. K. who was terminally ill, very depressed about her condition and very reserved. I reached out to her in every possible way, but she kept herself at a careful distance. At times I tried to hold her hand but she would always pull her hand slowly and carefully back. I made a point of watching the family when they were gathered around her bed—not once did I see her husband or her two daughters touch each other or touch her. When she finally died they looked at her, turned around and walked away. It

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<sup>104</sup>Loma Feigenberg, "Humane Death," Lakartidningen, L (1971)

<sup>105</sup>James N. Lapsley, Salvation and Health (Philadelphia: Westminster Press, 1972), p. 147.

seems to me that there are families where all touching is off-limits! We must not forget, however, that touch is a two-way sense. Not only does touch convey what we mean, but it tells us a good deal about the person we touch. Touching another person is the quickest way to find who doesn't like to be touched. Failing to respect this would be a mistake! Touch reveals taut muscles and sweaty palms. Through touch we can learn to know another person whom we are trying to help.<sup>106</sup>

Many terminally ill patients with deteriorating bodies because of the disease and those who had mutilating surgery and consequently are struggling with a loss of body image need special care and attention of the pastor. Here, probably more than in any other condition of disease, the patient needs someone to reach out through the misery to reclaim her/him as a human being. This is the most difficult kind of experience that will face the pastor. He has to visit such patients often, sit with them and touch them.<sup>107</sup>

In cases where a mastectomy is done, it may be helpful to the patient if the pastor in cooperation with the surgeon could interview the couple preoperatively to explore feelings about the anticipated mastectomy. If the preoperative marital relationship has been intimate and mutually supportive coping with the postoperative period will present fewer problems—especially now that the patient is

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<sup>106</sup>Earl Grollman, Concerning Death (Boston: Beacon Press, 1974), pp. 34-5.

<sup>107</sup>Robert B. Reeves, "Pastoral Care of Patients With Oral Cancer," Journal of Thanatology, 1:6 (1971), 538.

terminally ill. Where the husband reacts with repulsion and little support the pastor will know how to invest his energies.<sup>108</sup>

In cases where patients express severe anxieties and fears, whether rational or irrational simple explanations generally suffice. Whenever the patient asks a question, it is wise to determine what he really wants to know and then answer only that. As a member of the team the pastor is in an excellent position to discuss the patient's anxiety and/or fear with the physician and to ask the physician to explain the illness or simple procedures more to the patient. One way to reduce the patient's anxiety or fears is to re-arouse her/his creative impulses. Many dying patients become completely passive and just wait for the end.<sup>109</sup> By reactivating the patient's interest in creative activity whether painting or writing, etc., the beneficial effect will soon be apparent.

In cases where the patient is involved in anticipatory grief and depression it is important that the pastor will not only give permission to the patient, but encourage him to express a certain amount of the grief and the sadness. Not only does the patient experience subjective relief from verbalization and crying, she/he also feels closer to the person who was present to share the experience—provided that the listener was accepting and unhurried.

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<sup>108</sup>Schoenberg and Carr, "Loss of External Organs . . . ," p. 127.

<sup>109</sup>Hattie Rosenthal, "Psychotherapy For the Dying," Pastoral Psychology, XIV (June 1963), 55.

It is important not to cut the patient's venting of grief short by prematurely leaving or by false reassurance. The patient may then feel rejected and probably more lonely than if she/he had never been persuaded to talk in the first place.<sup>110</sup>

If the patient expresses a sense of guilt the pastor can be instrumental in helping to heal the wounds of a life-time; of bridging a gap that may have endured for years, of making the time of dying a time of renewing and re-finding of love between two people.<sup>111</sup> The pastor is also in a position of listening to guilt feelings in privacy and emphasizing the forgiveness of Christ our Lord.

The pastor is, in a certain sense, mediator between the patient and the family. Explaining and interpreting some of the less understandable behaviors of the patient to the family. She/he is also instrumental in alleviating tensions that develop almost automatically in such a time of stress.

At times the pastor can be mediator between patient, family and the medical personnel, expressing needs and problems. It is important that the team will recognize the pastor in this role.

The pastor is also, however hesitantly, mediator between the person and God; the God she/he understands only partially through the Revelation of His Word, desiring to learn to know and to understand God better in her/his contact with people. The pastor is in danger

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<sup>110</sup>Verwoerd, Communication with the Fatally Ill, p. 83.

<sup>111</sup>McNulty, "Meeting the Problem of Communication . . . ," p. 67.

of seeing her/his faith as her/his property, not willing to allow the struggling and the doubt, which keep her/him from moving with the patient and the family into a personal, alive, renewed faith.<sup>112</sup>

The pastor may find that the patient and/or the family will test her/him with what seems to be theological questions—about the goodness of God, the meaning of suffering, the purpose of life—and the pastor may be trapped into trying to give theological answers. These may silence the questioner, or turn her/him off, but they do not really help. People seldom ask what they seem to ask. Rather, they are asking "Does anyone understand what this is like? Does anyone care? Do I have to face all this alone?"<sup>113</sup> They are asking the pastor for acceptance, understanding and love in their misery. They do not know if they can count on her/him for that, so they test her/him.

There are many reasons for being available even when the patient has lost consciousness. The state of consciousness may fluctuate and in the short lucid periods the patient can gain much comfort from continuing communication with a friend newly acquired in the final phase of life, but from whom she/he has no difficulty to part. If the pastor stops visiting before death the relatives may experience this as an aggressive act towards them. During this time

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<sup>112</sup> Brands, In de Schaduw van de dood, pp. 132ff.

<sup>113</sup> Robert B. Reeves, "Pastoral Care of Cystic Fibrosis Patients and Their Families," Journal of Thanatology, 1:5 (1971)

the pastor can invest all his energy in the family and help them work through their anticipatory grief.<sup>114</sup>

When there are no personal ties with a family the pastor should not impose her/his presence on the family during the final hours when the patient is comatose and the family wants to be with the patient in privacy. I have found that families would let the pastor know—verbally or nonverbally, where they are and whether they want her/him around or not. The pastor should respect their wishes and still be available. In many cases the family reached out to the pastor after the death had occurred.

The creative sensitive pastor who had established contact with the patient and the family will, through communication, prayer, Scripture reading, sacraments stimulate spiritual growth that brings peace and a new relationship with God.

Many patients complain that they feel isolated from God, unable to make contact. I may offer to pray on their behalf, but will always ask the patient what her/his needs are and what they want me to ask God.

I have also found that death premonitions offer an avenue of possible assistance to the dying person. It should be respected.<sup>115</sup>

One morning I was called by a terminally ill woman. She said: "Chaplain, I'm going to die today. I don't want you to talk. I just

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<sup>114</sup>Feigenberg, "Humane Death."

<sup>115</sup>Robert Kastenbaum, "Premonitions of Death and Their Implications For Psychological Intervention," Division 22 Bulletin (March 1969)



want you to sit with me and hold my hand."

I went to the ward sister who told me that she may last for another couple of days. It was with reluctance that I took my place next to her bed, holding her hand. She died peacefully three hours later.

At times the patient may choose one person<sup>116</sup> to accompany her/him to the very end. This may be a spouse, a nurse, a social worker or a family member. The sensitive alert pastor will become aware of this and will direct her/his attention in a special way to that person, whosoever it may be. The pastor will be supportive, helping the person to continue day after day until death finally comes.

Only the skill which comes from training and studies, experience and a loving spirit, together with ruthless self-honesty, can provide the ground-bed for our pastoral care of the terminally ill patient.<sup>117</sup>

#### 7.6 The Family: Spouse and Children

Society has developed institutionalized means for handling the death experience, but society has not been nearly so ingenious in the developing of devices to cope with the terminal period.<sup>118</sup> The

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<sup>116</sup> Esther Hoffman, "Don't Give Up on Me," American Journal of Nursing, LXXI:1 (January 1971), 62.

<sup>117</sup> Leonard Tyler, "Ministry to the Dying," in Gilbert Cope, Death, Dying and Disposal (London: S.P.C.K., 1970), p. 32.

<sup>118</sup> Sol Levine and Norman A. Scotch, "Dying as an Emerging Social Problem," in Brim, The Dying Patient, pp. 218-219.

consistently casual treatment of family members in almost all hospitals proves that medicine does not yet consider the family an important part in patient care. Families and friends of dying patients can become as bewildered and neglected as the patients themselves. Because of their lack of time, taste or training, doctors can be expected to encourage or counsel families only so far or so long. Doctors yield to busy nurses or maybe to chaplains, who in turn yield to morticians.<sup>119</sup> The medical team considers the physical pain of the patient and it is treated but the mental pain and agony and suffering of the loved ones often is not even considered. In our big teaching hospitals I found that at times a patient may die without the physician meeting the spouse personally. She/he may have had a telephone conversation with the spouse but could not grant an interview because of a busy schedule! In most cases she/he did not know how big the patient's family was; as a matter of fact, she/he just did not care! Turning to the chaplain-pastors the situation was exactly the same. They may know the patient, but if they didn't run into the spouse or the children by accident, they didn't know anything about them and they generally made no effort to learn to know them and minister to their needs. One young chaplain said to me: "I'm paid to visit the patients in this hospital. The family is not my responsibility. If they need or want help they may visit a counselor or a psychiatrist!"

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<sup>119</sup> Robert E. Kavanaugh, Facing Death (Baltimore: Penguin Books, 1974), p. 7.

And meanwhile the family is suffering and dying too—piece by piece; part by part. Those who have the personal resources—ego strength and a supporting community survive the ordeal. Those who have the financial resources may go into lengthy expensive psychotherapy and those who have neither the ego strength nor the money end up in hospitals themselves with psychosomatic problems and eventually in our mental institutions. Moriarty<sup>120</sup> found that research indicates that the loss of loved ones, especially through death, is one of the most important causes of major mental illness. These illnesses may start immediately after the death of a loved one, or they may appear much later in life. Children who lose loved ones, mothers, fathers or siblings, in their early childhood are profoundly affected by this. In many cases the development of the child is damaged, leading to serious mental illness in adult life.

Once one reaches out to the family, to the spouse and the children one becomes aware of the emotional trauma involved in the terminal illness of a loved one. During my ministry I have talked to many family members of terminally ill patients. They expressed many different emotions at different times. I was touched by the sensitivity and introspectiveness of Lyn Caine who described her ordeal during her husband's illness in her memoirs Widow.<sup>121</sup> Her husband Martin died of cancer in the Marine Hospital, Baltimore on May 13,

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<sup>120</sup>David M. Moriarty, The Loss of Loved Ones (Springfield, IL: Thomas, 1967), p. 13.

<sup>121</sup>Caine, Widow.

1971 at the age of 51. I would like to quote some of her feelings and emotions.

I was afraid. And I was aching to talk about it. Usually I am a very private woman, but during these months I talked to people at any and every opportunity. Strangers, people for whom I wouldn't have to role-play.

During those deathwatch months I had absolutely no interest in sex.

I felt very guilty about the children in the months Martin was dying.

I was always full of guilt. Sometimes I would find myself laughing. I would have forgotten what was going on in my life for a moment. Then, 'How can I laugh?' I would chastize myself. 'Martin is dying!'

Martin's dying . . . I-hate-him . . . Martin's dying . . . What-will-become-of-me??? Martin's dying . . . I-wish-he'd-hurry-up . . . Goddamn him . . . Die-damn-you-die-Martin . . . No-Martin-live . . . I-love-you . . . I'll not exist without you . . . I'm-nobody-without-you . . . Martin-how-can-you-do-this-to-me? . . . And the children . . .

We had been a couple who 'communicated' . . . But now there was nothing to talk about. Not for us.

During the last months of Martin's life, I felt very strongly that I was being selfish. Extremely selfish. And this changed our relationship too. I became self-conscious.

Death is an experience of a conflicting nature for the family.

I wonder whether an outsider can ever comprehend what it is like to be caring for a loved one day after day after day; or visit the hospital evening after evening and seeing your beloved melting away, disintegrating, when cancer overtakes every organ of the body. It's impossible even to imagine it!

Lynn Caine was faced with feelings of profound loss and hopeless despair, often experiencing ambivalent feelings of love and hate, while the illness, like a giant python, gets its coils around her and the children; around the whole structure of their lives, changing everything, often threatening to destruct what became so important.

For a family to deny that they are gradually losing parts of themselves in the terminal illness and death of a loved one is to deny that they have ever loved.

The different family members will react in various ways to the threat of terminal illness. What these reactions will be is determined by a variety of factors—the strength of the family system; the degree of openness, communication and sharing; the support for each other in the family; the support received from the community; the ego strength of each individual, the attitude towards illness and death and dying, the financial situation; the importance of the limitations placed on the family; the amount of sacrifice asked from the individual members; the length and intensity of the terminal illness, etc. Most important perhaps is the place the patient holds in the family and the feelings the family has for the patient, whether the patient is the father (the sole breadwinner), the patient is the mother (the source of emotional stability and security), or fills some other role.

The family may react with shock and disbelief to the diagnosis of terminal illness. The decision to share this with the patient and talk openly about the illness, the diagnosis and the prognosis may bring a sense of relief; a sense of a shared burden; a sense of "We are in it together—as a family!" Whereas, the decision to keep it from the patient, the "conspiracy of silence" may add an extra burden to the already anxious and emotional family.

### 7.6.1 Hospitalization and the Family

The meaning of hospitalization to family members can best be understood if we keep in mind the community's attitude towards hospitalization in general and admission to a hospital for a terminal illness in particular. For many the hospital is the place to die.<sup>122</sup> When it becomes necessary to hospitalize the patient further emotional stress occurs because even though hospitalization may have been recommended by the physician, the family may guiltily feel that they have in some way rejected the patient. Consequently defenses are then erected around this guilt which further complicate the situation.<sup>123</sup> Then, to make amends, the family may spend much time around the sick bed, trying to do all sorts of things for the patient. They may try to shoulder some of the nurse's regular duties and end up by antagonizing the medical personnel through their well-meant, but naive and awkward attempts at assistance. When this happens, another disturbing ingredient is added: they perceive the irritation that they are causing the hospital personnel. At the same time, their frequent visits and sleepless nights in the patient's vicinity, sometimes trying to sleep on the chair in front of the bed, sometimes even stretching out on the floor for an hour or two because of the lack of adequate facilities for families, lead to further exhaustion,

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<sup>122</sup>Field, Patients Are People, p. 207.

<sup>123</sup>Verwoerd, Communication with the Fatally Ill, p. 116.

resentment and guilt.<sup>124</sup>

Despite the difficulties in caring for a terminally ill patient in the home, her/his removal does not eliminate problems for the family; it merely shifts the focus of their concern. While the patient was in the home the family may have had the heavy physical burden of caring for her/him, and the emotional burden of watching the suffering twenty-four hours a day. Now, the patient's absence, the anxiety about her/his condition from hour to hour, may create an atmosphere of tension with resulting disorganization and purposeless or frenzied activity, as if by such activity the family can fill the gap. The whole routine of family living may become centered on hospital visiting hours, requiring adjustments in their accustomed routine which may not come easily.

Because of the atmosphere of illness, suffering, and death traditionally associated with hospitals, family members as well as patients react with fear and misgivings. They too are awed by the unfamiliar surroundings and bewildered by the impersonal routine. While the patient, uncomfortable and fearful though he may be, knows at least how she/he is feeling and, in part, what is happening to her/him, family members are left in the dark. They try endlessly to contact the physician; first to get a personal interview in order to discuss the patient and the illness; to ask the thousand and one questions they have on their mind. Not succeeding they try to reach

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<sup>124</sup>Ibid., pp. 122-123.

him by telephone, making a thousand calls, leaving messages for him to return their call—but in vain. Eventually they give up in disgust and now they can only feed on their own fears and anxieties, continuing at the same time to cope with the many hardships the patient's illness creates in the home. Beset by these numerous problems, they may feel left out in the cold as they see all the care and attention lavished on the patient.<sup>125</sup>

Incredible and unbelievable is the suffering and agony imposed on the family by the sometimes inhuman bureaucracy of the hospital. Lynn Caine<sup>126</sup> tells about the arrangements that had to be made for Jonny their son (± 9 years old) who was so obviously distressed, so unhappy without his father, to see his dad. Martin would come to the window and wave at his son who was driven past the hospital in a car.

'There's Daddy,' I said, 'Wave to him.'  
Very tentatively, Jonny raised his arm. Finally he waved.  
'Wasn't it nice to see Daddy?'  
'That wasn't my father,' Jonny said firmly.

When hospitals have no facilities for aiding families (and most hospitals do not have such facilities) and does not require the staff to help the family, then family members are likely to be treated as "non-persons" and totally ignored. Glaser and Strauss<sup>127</sup>

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<sup>125</sup>Field, Patients are People, pp. 207-208.

<sup>126</sup>Caine, Widow, pp. 70-71.

<sup>127</sup>Barney G. Glaser and Anselm L. Strauss, Awareness of Dying (Chicago: Aldine, 1974), p. 171.



reports on one such hospital for lower class people where only the staff whose hearts were "touched"—"These people are so neglected"—would bother to stop and talk with relatives, sometimes offering them a cup of coffee.

#### 7.6.2 The Family and Change in Role Behavior

Terminal illness threatens the integration of the family because it encroaches upon the family composition. The degree to which the terminal illness represents a crisis situation for the family members will depend on the changes in roles within the family system. The balance and interactions within the family system will be disturbed. The patient may have filled the role as the family leader or as the family scapegoat. Her/his move into the sick role may call for a substantial reconstitution of family patterns.<sup>128</sup>

Reorganization takes place within the family, with new patterns of relationships established in order to fill the gap in the group vacated by the patient.<sup>129</sup> Another family member or members may have to assume the position previously held by the patient. Moreover, the tasks involved in caring for her/him, particularly if she/he is at home, may require readjustment of other family functions. A working wife or mother may have to give up her job to care for a sick husband

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<sup>128</sup>David Maddison and Beverley Raphael, "The Family of the Dying Patient," in Bernard Schoenberg (ed.) Psychosocial Aspects of Terminal Care (New York: Columbia University Press, 1972), p. 193.

<sup>129</sup>Verwoerdt, Communication with the Fatally Ill, p. 116.

or child. There may be insufficient time and no particular inclination to fill previous leisure roles, and the mother of a dying child may no longer be able to fulfill her sexual role with her husband. There will be an additional work load if she has to fill the roles of both nurse and breadwinner, as well as the problems of role conflict. Changes in role expectations within the family may occur, and disintegration may result if the consensus necessary for homeostatic balance is not achieved.<sup>130</sup> The changing of roles is always anxiety provoking. Often this involves the giving up of things which were previously considered as important in the individual's life. This may engender further hostility, anger and guilt within the family.

Often the change of roles may be welcomed and work out so well that subsequent problems arise when the patient returns home during a brief remission. Feelings of resentment towards the medical profession and even toward the patient may further disrupt the recently attained family equilibrium.

#### 7.6.3 The Family and Anticipatory Grief

Following the initial phase of shock, with its disorganizing depersonalizing effect, a fuller realization of the loss begins to dawn upon the family and the emotions of sadness and grief are acutely

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<sup>130</sup> Maddison and Raphael, "The Family of the Dying Patient," p. 193.

and painfully felt.<sup>131</sup> A relative may go so far as to lose control of his emotions and actions, resulting in anything from silent stupor or aimless wandering about to wild agitation. She/he may be numbed and dazed, with the subjective feeling that her/his personal world has collapsed or is incomprehensibly altered. Her/his consciousness may be clouded with resulting confusion, misinterpretations of reality and illusions.

The family members may be involved in "grief work" and work through many of the deeper feelings before death actually occurs. Their grief may be shared with the patient who stands to be cut off from all he has known and loved. This may be a healthy and sustaining relationship, and setting the stage for a mature and competent handling of the event of death itself.<sup>132</sup>

Anticipatory grief work that is being done and completed can also result in many problems for the family. James A. Knight and Frederick Herter describe such a situation.<sup>133</sup>

I am acquainted with a physiologist, on a university faculty, who for the past ten years has had Hodgkin's Disease. When his illness was first diagnosed, it was thought he would live for only a few months, but he recovered sufficiently to return to his teaching and research. Periodically, though, he has had a severe exacerbation of his illness which has required hospitalization for weeks or months. During each of these periods of hospitalization, he has not been expected to recover. Yet, he has recovered and

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<sup>131</sup>Verwoerd, Communication with the Fatally Ill, pp. 130-131.

<sup>132</sup>Bowers, Counseling the Dying, p. 62.

<sup>133</sup>James A. Knight and Frederic Herter, "Anticipatory Grief," in Kutscher, Death and Bereavement, p. 198.

returned to his family and to work. During his remissions, each of which usually lasts for several months, he performs most of his duties at a high level of effectiveness and continues to do creative work in research.

Each time he is discharged from the hospital and returns home, a genuine crisis in interpersonal relationships develops. Hostility seems to flow in every direction. His wife and four children seem to have great difficulty integrating him again into the life of the family. Thus diverse complications arise which almost break the structure of the group.

In discussion of this problem with the brilliant and perceptive wife, who, like her husband, is a university professor, it became obvious what was happening. Each time the husband and father went to the hospital, the wife and children expected him to die because of the gravity of his condition. They began to mourn his loss. In order to prepare themselves for the seemingly inevitable death of their loved one, they began to mourn for him in advance (anticipatory grief). When he did not die, but returned home after weeks or months, the family members had already to a great extent broken their ties to him. Then they were faced with the problem of reintegrating into their lives the person they had already given up.

The wife was helped to see what was happening. She was amazed that she and the children did not realize what they were doing. Now that she understood the situation, she was able to prevent the storm which had previously followed each of her husband's discharges from the hospital.

#### 7.6.4 The Family and Anxiety

Even a loving and supporting family may have great anxiety in the patient and in the other members of the family. It is not enough to say that the anxiety is related to the fear of death.

The fear of dying is a matter distinct from the anticipation of death. The fear of death, of which so many patients speak, is in fact a specific attitude toward the process of dying, and is not related to the fact of death. It pertains to a sense of imminent disintegration, collapse, or dissolution, and hence is more closely allied to primary anxiety or panic than to the transfiguration that

death entails.<sup>134</sup> Certainly, most people have a fear of dying, even if it represents nothing more than an adventure into the unknown. Reasons for the anxiety may be problems with interpersonal communication, indicating areas of unresolved tension between the patient and the family. The family may be overprotective, keeping the patient from making decisions for himself. This may provoke anger and resentment and also a feeling of helplessness. The patient may feel unable to express her/his negative feelings towards her/his family for fear that she/he may be further isolated from the outside world. Frequently the family-members may cause many problems for themselves, for their loved ones, for the patient and for the medical staff because of tensions in regards to their demands on the dying person which is not worked through.<sup>135</sup>

#### 7.6.5. The Family and Their Anger

Anger and hostility in the relatives may arise from several sources. The patient's illness imposes an emotional and economic drain upon the family. The constant strain of caring for the patient and meeting heavy financial obligations often becomes so great that irritability develops. These feelings are further aggravated when,

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<sup>134</sup> Avery Weisman and Thomas P. Hackett, "Predilection to Death," in Robert L. Fulton (ed.) Death and Identity (New York: Wiley, 1965), p. 308.

<sup>135</sup> Earl Grollman, Concerning Death (Boston: Beacon Press, 1974), pp. 62-63.

despite all the sacrifices and efforts, the patient does not get better.<sup>136</sup>

The fact that dependency needs are now ungratified is in itself sufficient to mobilize the family members' aggression. The patient, either at home or in the hospital restricts the activity and freedom of the family. If they had an active social life in the past, they may find themselves only visiting the hospital every evening and staying at home the rest of the time. Especially in cases where the illness is long and lingering the family may resent this and become very angry. The aggressive reactions may appear in overt form, they may be displaced to other objects or persons (medical staff), even to the extent of the formation of phobic symptoms, they may be internalized resulting in severe depression, or overcompensated by reaction formation to produce excessive concern and spoiling the patient.<sup>137</sup>

Anger towards the patient may result in guilt feelings: "How can I feel that way? She/he is dying! I shouldn't be angry and frustrated!"

#### 7.6 The Family and Their Guilt

Clinical observation shows that guilt, no matter how weak its foundations in reality, is common in relatives of seriously ill patients.<sup>138</sup> Continued existence of guilt in family members

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<sup>136</sup>Verwoerd, Communication with the Fatally Ill, p. 128.

<sup>137</sup>Maddison and Raphael, "The Family of the Dying Patient," pp. 189-190.

<sup>138</sup>Stanford Friedman et al., "Behavioral Observations on

complicates the successful resolution of their grief by prolonging the period of bereavement, to such an extent after the patient's death that a rather serious depression may result from their inability to emotionally disentangle themselves.<sup>139</sup>

Guilt may develop in terminal illness in cases where the illness is extended over an indefinite period of time. The frustration, anxiety and irritation generated by the illness and the caring for the patient may result in interpersonal conflict with the patient. Relatives may also overextend themselves in the care of the patient to the point of exhaustion and subsequent resentment. On the basis of conscientious dedication, the relative suppresses these wishes for rest and relaxation, and attempts to deny the realization that, underneath it all, she/he sometimes tires of her/his commitment. She/he may even catch her/himself wishing it were all over. At this point she/he is ashamed of her/his impulses and so resolves to put forth extra efforts to be considerate and helpful. Thus the "extra efforts" lead to further fatigue, strain and wishing to be relieved so that a vicious circle is set in motion.

The family may also experience guilt when the patient has to be hospitalized; interpreting hospitalization as their own rejection of the patient out of the home and family.<sup>140</sup> Guilt may also appear if the family member feels in any way responsible for the illness,

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Parents Anticipating the Death of a Child," Pediatrics, XXXII (October 1963), 610-625.

<sup>139</sup>Verwoerd, Communication with the Fatally Ill, p. 121.

<sup>140</sup>Ibid., p. 122.

such as may occur with hereditary fatal diseases, or if the family member believes or fears that her/his own neglect, anger, prejudice, or interference has contributed to the fatal outcome.<sup>141</sup>

#### 7.6.7 The Family and Defense Mechanisms Employed<sup>142</sup>

The family-members may use a variety of defense mechanisms to help them cope during this traumatic period.

1. Denial: It is one of the major defenses mobilized during these circumstances and is often used in excessive degree. It tends to be exaggerated when parental guilt is marked, or when diagnosis has been delayed, and is maintained longer for those persons at a greater social distance from the dying person—for example grandparents and distant relatives.

2. Isolation of affect: It may appear as a healthy coping device enabling the relative to perform the necessary practical functions for the terminally ill patient in a rational way. If used excessively it may lead to withdrawal from the patient as though she/he were "already dead."

3. Sublimation may enable the family member to deal more appropriately with practical problems.

4. Repression may become excessive, as may reaction formation,

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<sup>141</sup> Maddison and Raphael, "The Family of the Dying Patient," p. 190.

<sup>142</sup> Ibid., pp. 191-192.



particularly in the presence of major problems with aggressive wishes and frustration of dependent needs.

5. Displacement of hostility is especially likely to occur; it may become attached to other family members, or to medical or nursing personnel. Dependent and sexual needs may also be displaced to other family members or outside agents.

6. Projection, particularly of hostile and dependent wishes, may occur on to the patient or another family member.

7. Introjection of aspects of the patient may occur, with the family member taking on her/his illness and/or personality characteristics as a defense against the imminent object loss.

#### 7.7 Pastoral Care of the Family

And so the priest came. Flushed. Panting a little. Swooping in. Like a bird of prey, I thought. With a little black suitcase. Thick Irish brogue. His moment. Soft-tongued. Superior. 'Would you leave the poor, poor man alone with me for a few moments, Mrs. Frick?'

I hadn't bargained for that. What, leave Miecú on the very edge of death? To have come so far only to leave him in the very last moment? The man must be mad, I thought. I wouldn't dream of it. 'I'm sorry, Father, but that is quite out of the question. I wouldn't dream of leaving my husband at a time like this.'

'You really must. I must insist. Just a few moments. I have to do my job.'

I was cut by his preremptory attitude. My heart burned with indignation.

'I'm afraid you will have to do what it is you have to do in my presence or not at all, Father. I won't give him up yet. I'm sorry.'

'But it is most unorthodox.'

'This is no time to worry about what is orthodox and what isn't, Father. I will not leave my husband and if you are going to make a fuss then I am afraid I shall have to ask you to leave. You are here, after all, at my suggestion. Not at his.'

He hovered uncertainly over the bed for a while, his lips in a thin, furious line. Then he leaned over Miecú. Poor, staring,

unseeing Miecú. Could he hear this verbal tug-of-war going on over his tattered bones? I hoped not. Father P. looked intently into Miecú's face. 'Doctor?' he asked. 'Are you sorry for your sins?' The sister paused on the point of leaving the room. 'He is quite unconscious, Father,' she said. 'He can't hear you.' The priest persisted. 'Doctor, are you sorry for your sins?'

Of course there was no reply nor any flicker of understanding. Miecú was gone from us leaving only a long wordlessness and the sound of water gurgling thickly in his chest and his breath coming short and fast. The fingers that were clasped so tightly around my wrist were quite cold now. Icy. Totally unresponsive. The eyes that were frozen in his face were filled with greyness. Fixed beyond me. Beyond the room. Beyond the horizon. He could never see me again.

The priest took hold of Miecú's free hand.

'If you are sorry, Doctor, press my hand.'

I stared at him in amazement, struck by the futility and the utter fatuousness of the whole situation. And then something burst in me. Rage. Grief. Revolt. Scorn. Disgust. I don't know what. A mixture of all things, I suppose. Hostility and disappointment certainly. Keen disappointment. Because secretly I had hoped for something from this moment, for some sort of comfort, sustenance, some key that would open my heart and my eyes to God. I had no God, but I badly wanted one, and in the moment of Miecú's dying I was as open to God as much as I would ever be. But there was nothing. No light. No rolling of drums or clashing of cymbals. No writing writ large upon the wall. Only this cold impersonal priest with his ritual incantations and the darkness looming and Miecú and me facing it unarmed and uncomfórted.

'For heaven's sake, Father!' I burst out. 'He has no sins.'

The priest looked up at me. He was white-faced. taut-lipped and trembling a little. We glared at each other like enemies across the grave.

'Can you answer for him, Mrs. Frick?' he demanded sharply.

'Can you, Father?' I retorted bitterly.

Miecú died at 6:15 p.m. that Sunday . . . . There was no death rattle. No final agony. Just a slight rigor, a faint sigh escaping his lips, his head flopping slackly over to one side, and a trickle of saliva slipping out of the right hand corner of his mouth. I closed his eyelids and kissed them . . . .<sup>143</sup>

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<sup>143</sup>Frick, All the Days of His Dying, pp. 138-140.

Even the broadened goal of medical science, however will fail to achieve its ultimate objective as long as we continue to confine our interest to the individual who comes to us for help. For the patient is not alone in his suffering; no patient is an isolated individual; no one lives in a vacuum. Like a pebble thrown into water, illness causes ever expanding circles, affecting not only the person who is ill, but his family.<sup>144</sup>

The family represents the basic community. The dying patient feels isolated and alone. To be held close by her/his family during the closing events of life eases the emotional pain. If the family can take a healthy view of death and dying they can stand in close relation to the patient. This may not involve many words. Often the patient, without saying anything will move her/his eyes and look about the room, or will feel the touch of a hand upon hers/his, and will know that in the lonely pilgrimage into death, those who love her/him have not deserted her/him in their fears, but are standing by in their desire to share her/his life to the end.<sup>145</sup>

Although each person makes this journey in her/his own way, observation indicates that it is less difficult if members of her/his family journey with her/him. But family members are also people; finite human beings with human anxieties and fears and feelings; human beings in need of support and love and caring. Not only are they

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<sup>144</sup>Field, Patients are People, p. 201.

<sup>145</sup>Bowers, Counseling the Dying, p. 61.

treated like intruders with no right to be with their loved one during the final hours, but, at times, they are totally ignored and rejected by the personnel of our modern hospitals! The patient becomes the only object to be treated. She/he is the sole concern of the team. The chaplain pastor, the representative of a compassionate God and a loving, caring Church is no different from the other members of the team. The family does not really exist for her/him in the majority of cases! The minister-pastor does not act much different from her/his brother, the chaplain. I have listened to many conversations between the parish minister and "his" parishioner, meeting each other in the hospital. The minister will inquire about the parishioner's family member who is terminally ill, but never is a word said or a question asked about the parishioner family-member's own health, needs, wants, coping devices, etc. It must be either unimportant or the family member must be considered to be superhuman with superhuman coping devices. Family members are human. They do need sustained help, recognition of the burden they are called upon to carry and an opportunity to voice their frustration and grievances.<sup>146</sup> The caring team in our hospitals must reevaluate their priorities and responsibilities. The team can offer support which helps the family during this difficult time. It takes time and availability on the part of the staff, but once the family has accepted the approaching death and are convinced that the patient, too, can accept it, the way

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<sup>146</sup>Field, Patients are People, p. 210.

is open to a shared peace. When they have accepted together the reality of the final illness and the impending death, the burden is lifted and they are free again to start living together—until the patient finally dies.<sup>147</sup>

According to Eissler<sup>148</sup> the priest or minister is in a more favorable position to minister to the needs of the dying patient, since he is a representative of the power beyond, before which the faithful who is dying, believes she/he will soon appear. Since the psychiatrist does not have this advantage she/he must first establish the platform which the pastor finds ready made in each instance in which he is called for consolation to the bedside of a dying person.

In a study done by Ann Cartwright et al.,<sup>149</sup> in England, it was found that only 29% of the people questioned, reported that they received help from a priest, minister or church worker, during the terminal illness of a family member. 33% of the elderly people above 65 years reported that they received help from a priest, minister or church worker. She also found that only 4% of the people questioned talked to the pastor after death. Only 2% of those who had talked to a pastor found that the pastor was helpful. These findings may give

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<sup>147</sup>Zita Marie Cotter, "On Not Getting Better," Hospital Progress, LIII (March 1972), 60-63.

<sup>148</sup>Eissler, The Psychiatrist and the Dying Person, p. 247.

<sup>149</sup>Cartwright, Life Before Death.

us an indication of what we can expect to find in other countries in Western Society.<sup>150</sup>

A family must be studied and evaluated with the help of the different disciplines available in the hospital setting. All the pertinent aspects of the family must be understood, such as financial ability, other obligations, other illness, psychological and social relationships affecting the family's ability and willingness to help the patient. The teamwork should extend into the home. The background information may help the pastor in her/his understanding of the motivations and patterns of behavior of individual members.<sup>151</sup> As in the case of the family of the terminally ill child I want to point out that the pastor must proceed in helping the family in crisis situations without struggling to obtain information.<sup>152</sup>

Sometimes we overlook some of the positive forces in family life we can draw upon. We are likely to forget that family living not only creates problems for its members at times, but is also a source of strength. In our culture, the family as a unit provides the best opportunity for growth and fulfillment, the place where the individual can best express her/his natural potentialities and satisfy her/his creative and motional needs. Even when society apparently casts out an unproductive member (terminally ill patient), the family

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<sup>150</sup>Ibid., p. 193.

<sup>151</sup>Cancer Care Inc., Catastrophic Illness in the Seventies (New York, 1970), p. 119.

<sup>152</sup>See Chapter 6.5.

circle can be counted on to provide such loyal support, affection, sympathy and understanding that, despite her/his handicap, the terminally ill person can continue to participate in everyday life.<sup>153</sup>

The pastor needs to identify the support system which is operating within the family, the strengths and potentialities which are available (sometimes latent) and help the family members to become aware of it and draw on it. This could assist in resolving the impact of the terminal illness on the family.

The total family is affected by the illness, and their reactions among each other and to each other are terribly important. What strengths can they draw from each other as they face the problem? How can they support each other with the available potential? Sometimes as the patient works through her/his own problems in relation to her/his feelings, she/he sustains the family, comforts and supports them when they are unable to face the reality and vice versa. The pastor can play a very important role by interpreting the meaning of the patient's behavior to the family in a way that would enable them to transcend it. For example, the pastor may explain to the family that the change in the personality of the patient is due to physical conditions which make a person behave in ways contrary to his feelings. She/he attacks those she/he loves and accuses those she/he trusts most. Usually such explanations make it

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<sup>153</sup>Field, Patients are People, p. 130.

easier for the family to adjust to the behavior that threatens them and complicates their relationship with the patient.<sup>154</sup>

It is important that the pastor should aim at bringing the family together, helping them to understand each other. Only then can pretense be dropped and during the last days together, they can be real people. If the family has never been warm and close in their relationships, it is best not to tamper with them. In these cases it is best to withhold judgment and support the families in their accustomed roles.<sup>155</sup>

Theoretically physicians are available to members of the family during visiting hours; actually, they are seldom in evidence, being busy elsewhere. If relatives succeed in finding a doctor to answer their questions, privacy and sufficient time are often lacking so that many of the questions that are troublesome remain unasked and unanswered.<sup>156</sup> Throughout the family there will be a sense of lost and of being lost. If they can talk easily about their problems or know they can reach the sympathetic ear of a competent person also involved in the care of the one they love, their own sense of insecurity will be eased. If the family can have help and empathy when they need it, the terminally ill person in turn will reap considerable benefit. She/he is usually immensely concerned over the family she/he

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<sup>154</sup>Cancer Care Inc., Catastrophic Illness in the Seventies, p. 111.

<sup>155</sup>Virginia Barckley, "Grief, a Part of Living," Ohio's Health, XX (April-May 1968), 34-38.

<sup>156</sup>Field, Patients are People, p. 211.



is about to leave.<sup>157</sup> The pastor can act as a valuable liaison between family and physician; between the family and the team.

The pastor can also set the tone for the sickroom, not of gloom, but of confidence and peace, not of any false assumption that the patient is going to recover, but on the true basis that God is in control here. Particularly the pastor can help by watching during the long night hours and thereby spelling out relief for the family, as well as supplying the ministry of the Church.<sup>158</sup>

More than anywhere else, it is necessary to encourage expressions of emotions in grieving relatives, because conscious recognition of the loss and the concomitant feelings of grief represent the first step toward successful resolution of the mourning experience. This implies awareness and cautious removal of emotions and defenses which may obscure or distort grief, such as anger, denial, rationalization and intellectualization, etc. Any emotion which masks full recognition of the loss and prevents the expression of grief may lead to a prolongation of the grief reaction until it finally merges into an extended depression.

The management of grief during the shock phase is primarily nonverbal and supportive. The pastor should make her/himself available to the relatives throughout the acute stage as a strong figure

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<sup>157</sup>Hinton, Dying, p. 120-121.

<sup>158</sup>Edward G. Harris, "The Physician, the Clergyman, and the Patient in Terminal Illness, in Robert B. Reeves (ed.), Pastoral Care of the Dying and Bereaved (New York: Health Science, 1973), p. 46.

who can sustain them during psychological crisis, and during this time she/he should attempt to avert any possible hysterical reaction in an emotionally labile family member. In having firm limits set for such an individual, the family will be inwardly grateful that there is someone around who still has the situation in hand.<sup>159</sup>

In essence the goal of anticipatory grief therapy is to create a genuine spirit of openness wherein both patient and family can vent their internal feelings of doubt, hostility, and apprehension, and thereby enter on the road of becoming a whole person in the face of death.<sup>160</sup> If relatives of the dying patient can be helped to begin their grief upon discovery of the imminence of death; share in the process with the dying person her/himself, and complete the process after death, their needs and the patient's will be served. If the grief-process is encouraged to begin prior to the fact of death, the chances for an emotionally and religiously constructive resolution are enhanced.<sup>161</sup>

The management of anger requires that the pastor be alert to the possibility of its existence before it becomes full-blown and that she/he recognize its defensive function of self-reassurance. Recognition of the underlying need which the relative's hostility

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<sup>159</sup>Verwoerd, Communication with the Fatally Ill, pp. 129-130.

<sup>160</sup>Carlozzi, Death and Contemporary Man, p. 49.

<sup>161</sup>Buxbaum, "Grief Begins Not With Death . . . ."

serves will enable the pastor to better preserve an attitude of detached concern and avoid responding in a reflexlike manner with apologetic defensiveness or with counterhostility.<sup>162</sup>

In order to communicate effectively and reduce some of the stress which the family experiences, it is necessary to recognize their guilt and to encourage the family-member to deal realistically with the guilt. Because of the guilt-feelings they experience many family members will return to God, whom they had neglected for so long, and in doing so they feel guilty over what they sense a hypocritical action.<sup>163</sup> The pastor must listen in a caring supportive way, accepting the family member as she/he is and thus demonstrating God's acceptance, love and caring in spite of alienation. The pastor may help the person to confess her/his wrongdoings to God and accept forgiveness. It is most important that the person verbalize their guilt feelings, the pastor reassuring and supporting.

Guilt feelings may be appropriate or neurotic. How it is handled depends to some extent, on whether it is appropriate or neurotic. All guilt has its objective and subjective aspects. Objectively, appropriate guilt is the result of actual damage to persons; subjectively, it stems from the misuse of that degree of inner freedom one possesses. It is the consequence of violating the values which the mature side of one's conscience regards as authentic

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<sup>162</sup>Verwoerdt, Communication with the Fatally Ill, p. 128.

<sup>163</sup>Carlozzi, Death and Contemporary Man, p. 47.

and significant. In contrast, neurotic guilt feelings are produced by the immature side of conscience—i.e., values which were rewarded or punished by one's parents. This side is motivated by fear of punishment and rejection, rather than a positive striving for what one wholeheartedly affirms as good. Neurotic guilt results from breaking internalized parental prohibition.

In many people appropriate and neurotic guilt feelings are intricately intertwined. The neurotic elements can be identified by these characteristics: 1) They do not respond to the forgiveness process. 2) They seldom motivate constructive amends or changes in guilt producing behavior. 3) They seem to produce masochistic satisfactions.

The genuine and appropriate elements in a person's guilt feelings can be resolved via a five-stage process: confrontation, confession, forgiveness, restitution and reconciliation.<sup>164</sup>

The pastor and adults can do much to help a child through the loss of a parent. The pastor's role may be educative; explaining to and leading the family members in helping the child/children.

The illness and prognosis should be explained in simple, not greatly detailed terms, answering every question of the child as truthfully as possible, in terms consistent with the family's religious orientation. Death and grieving are new experiences for most children, who seek explanations either from supporting figures or

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<sup>164</sup>Howard J. Clinebell, Jr., Basic Types of Pastoral Counseling (New York: Abingdon Press, 1966), pp. 224-225.

from their fantasies and imagination. The child must be reassured that she/he in no way contributed to the illness or to the anticipated death of the parent. A relative or close friend or even the pastor her/himself can be of immense help by assuming the responsibility for guiding the child through the crisis, for those most affected by the death, including the spouse of the terminally ill patient may be so involved in their own loss and anticipatory grief that they are not able to comfort the child. The older child may react to the death of a parent in a manner similar to grief-reactions observed in adults.<sup>165</sup> The older child, though, may be more vulnerable to feelings of guilt because she/he has less experience with death.<sup>166,167</sup>

Introducing a pet into families that face the threat of a loss of a parent can, in many cases prove to be a valuable mental hygiene measure. The pet gives the child a living companion that will not usually be a competitor for the surviving parent's affections. Even more important, the pet represents a protector, a talisman against the fear of death, which is first experienced as separation anxiety. During the period of anticipatory grief the pet plays a

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<sup>165</sup>Erich Lindemann, "Symptomatology and Management of Acute Grief," Pastoral Psychology, XIV (September 1963)

<sup>166</sup>Stanford B. Friedman, "Management of Death of a Parent or Sibling," in Morris Green (ed.) Ambulatory Pediatrics (Philadelphia: Saunders, 1968), p. 781.

<sup>167</sup>Edna Furman, A Child's Parent Dies (New Haven: Yale University Press, 1974), pp. 17ff.

crucial role by providing the child with a sympathetic, non-judgmental listener before whom the child may become immersed in her/his grief and speak and cry unabashedly and repeatedly about the beloved parent and his own guilt in bringing about her/his death. When the parent dies the pet may become a temporary crutch that helps the child to hold on to life until the void can be filled and her/his shattered world can become whole again.<sup>168</sup>

For the adult, the death of a close relative is frequently a traumatic event. For the child, death of a close relative such as a father or a mother can also be a traumatic event, but, even more important, it constitutes a developmental interference and a very serious one indeed.<sup>169</sup> The pastor is the one person in a position to reach out to the child and the family; to love them and to care for them in an all inclusive way, following the example of her/his Master, Jesus Christ.

The pastor can be instrumental in helping to heal the wounds of a lifetime, of bridging a gap that may have endured for years, of making the time of dying a time of living; a time of re-newing and refinding of love between people.<sup>170</sup>

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<sup>168</sup>Boris M. Levinson, "The Pet and the Child's Bereavement," Mental Hygiene, LI (April 1967), 197-200.

<sup>169</sup>Humberto Nagera, "Children's Reactions to the Death of Important Objects," The Psychoanalysis Study of the Child, XXV (1970), 363.

<sup>170</sup>McNulty, "Meeting the Problem of Communication . . . , p. 67.

Marya Mannes<sup>171</sup> writes about her young husband who had died

after a terminal illness:

The importance to him was not so much to know that he would be mourned after he dies, but the reality of knowing that he was loved while he lived. Speaking freely of death allowed us to taste more fully life, those are the lessons the dying teach us.

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<sup>171</sup> Marya Mannes, Last Rights (New York: Morrow, 1974), p. 119.

**PART III**

**INTEGRATION**



## CHAPTER 8

### A THERAPEUTIC APPROACH TO DYING

Death is as old as humankind. The finality of death may not have changed throughout the centuries, but dying did indeed! In our modern society with its ultra modern hospitals dying is very often postponed. I have heard of one patient being resuscitated 105 times! But, eventually death cannot be sidestepped any more and comes close and becomes very real. Even at this point modern medical science is not willing to accept death and interferes crudely with what should be natural and logical. The patient is not allowed to die, but dying is extended over a period of time, maybe a day or two; maybe a week or a month or even longer. This means more pain and more suffering and more anguish; more isolation and loneliness for both patient and loved ones. There is nothing natural about it any more; only the buzzing of machines and tubes and drugs. It became almost impossible just to die.

Not very long ago the former president of the Union Theological Seminary in New York, Dr. Henry Van Dusen, and his wife Elizabeth swallowed an overdose of sleeping pills. Mrs. Van Dusen, 80 and suffering from arthritis, died within hours. Her 77-year-old husband, who had had a devastating stroke five years ago, died fifteen days later. In a letter to their friends and relatives the Van Dusens wrote:

We have both had very full and satisfying lives . . . . But since Pitney had his stroke five years ago, we have not been able to do

any of the things we want to do and were able to do . . . . There are too many helpless old people who without modern medical care would have died, and we feel God would have allowed them to die when their time had come . . . . Nowadays it is difficult to die . . . .

It is beyond the scope of this dissertation to enter into a debate over one's right to end one's life under conditions of one's own choosing; to discuss the whole problem of Euthanasia. I quoted this part of the Van Dusens' letter because I've heard this cry from many terminally ill patients in our hospitals, "Nowadays it is difficult to die," or "Dying is difficult."

We are confronted with the advance in modern medical science. We have to accept these, but we need not capitulate under these! The Christian Church has a very special task and responsibility in the presence of the medical-technical developments of our secular society. The church must evaluate its position and its ministry. The church must not get behind in its ministry to people because of a lack of trust, financial resources, manpower, and imagination. Believing in Jesus Christ and trusting the Holy Spirit, the Church must confront the problems and crisis of the terminally ill patient and the family and minister to their needs. It has been neglected for so long; it is time for action.

How can the Church help people live until they die? How can dying, although extended, become an opportunity for growth and fulfillment? There are some of the questions I will explore in this chapter.

8.1 St. Christopher's:<sup>1</sup> An Excellent Example of a  
Therapeutic Community For the Terminally Ill  
Patient and the Family<sup>2</sup>

St. Christopher's is a Christian and medical foundation, caring for those in pain and suffering because of advanced cancer or other long-term illness. They are welcomed into a community planned for them where they can stay as long as they are in need. Its aim is to show the love of God for such people in skilled nursing, in using all that modern medicine has to offer to relieve distress and in seeking to understand and share the problems of those involved.<sup>3</sup> Death as a fulfillment is the underlying assumption of Saint Christopher's. Cicely Saunders, the medical director of the Hospice writes, "The last stages of life should not be seen as a defeat of living, but rather as its fulfillment. It is not merely a place of negation, but a field for positive achievements. One of the ways we can help our patients most is to learn to believe and to expect this."<sup>4</sup>

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<sup>1</sup>St. Christopher's Hospice, 51-53 Lawrie Park Road, Sydenham, London. S.E. 26 6DZ, England.

<sup>2</sup>I spent December, 1974 in St. Christopher's, working as an orderly.

<sup>3</sup>All the information about St. Christopher's is obtainable from St. Christopher's.

<sup>4</sup>Harry S. Olin, "Failure and Fulfillment: Education In the Use of Psychoactive Drugs In the Dying Patient," in Ivan K. Goldberg (ed.) Psychopharmacologic Agents For the Terminally Ill and Bereaved (New York: Columbia University Press, 1973), p. 10.

### 8.1.1 History

St. Christopher's began when David Tasma, a lonely Polish man from the Warsaw ghetto, who was dying of cancer in a ward of 50 patients, opened up to Cicely Saunders who was a social worker at that time. David shared with Cicely Saunders what it was like to die in a big impersonal hospital ward. Both decided that dying can be better. Before he died he gave £500 "to be a window in your home." He said, "I want what is in your mind and in your heart." With the money in her hand and a dream, faith and love in her heart Cicely Saunders knew that she had a special task and that she had to do something about it—however long it might take.

Inexorably commanded by her inner convictions Cicely Saunders started to work. It was nineteen years before the first patient came past David Tasma's window and the first members of the staff began to try to give what was in their minds and in their hearts, to bring all they could summon of skill and friendship to relieve the manifold distress that has ever since been coming into St. Christopher's.<sup>5</sup>

### 8.1.2 The Hospice—A Family

Cicely Saunders described the Hospice as a place where individualization can take place.

The name hospice, a resting place for travellers or pilgrims, was chosen because this will be something between a hospital and a

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<sup>5</sup>Cicely Saunders, Faith (Guildford: Seven Corners Press, 1974), pp. 1-2.

home, with the skills of the one and the hospitality, warmth, and the time available of the other and beds without invisible parking meters beside them. We aim, above all, to recognize the interest and importance of the individual who must be helped to live until he dies and who, as he does so in his own way, will find his 'own death' with quietness and acceptance. A staff who recognize this as their criterion of success will not find this work negative or discouraging and will know that it is important, both in its own right and in its implications it holds for the rest of medicine and, indeed, the rest of life.<sup>6</sup>

The Hospice is an attractive new building in the center of a community, not hidden away in a corner. It is on a main road, near shops and a park, with tennis courts. There is plenty of activity which can be seen from the large windows. The wards are bright and give a feeling of space. It is difficult to believe that the patients are there for terminal care. The garden which surrounds the buildings is well planned and kept and is a much enjoyed meeting place for patients, staff and families during summer time.<sup>7</sup>

As over half the staff at St. Christopher's are working part time there is a modern nursery school/playroom for the children of the staff. There is a nursery trained nurse in charge. This has attracted many nurses back into the profession. Having the children around brings great joy to the patients, particularly out in the garden. The children have their lunch with their mothers and the rest of the staff and family members of patients in the main dining room daily. St. Christopher's has a residential wing for the elderly, who

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<sup>6</sup>Olin, "Failure and Fulfillment . . . ," p. 10.

<sup>7</sup>Verena A. Galton, "Cancer Nursing at St. Christopher's Hospice," in American Cancer Society, Proceedings of the National Conference on Cancer Nursing (New York: 1973), pp. 122-123.

have their own rooms which they furnish themselves and who are allowed to be as independent as possible for them. They also have their meals in the main dining room. They participate in the activities of the Hospice, attend chapel services and visit with patients. At times, when necessary, they sit with patients during the final hours. They add another dimension to the life in the Hospice and their presence most certainly gives a feeling of stability in an atmosphere where some 400 patients die each year.

There is a sitting room which is available for patients to use at any time. A volunteer serves tea every afternoon for patients and families in this sitting room. Each floor has its own day room, where, during the winter a cozy fire is burning and patients can spend their days. There is also a smaller, attractive furnished, room on each floor which is used by the staff for more private interviews with the family. During the final hours before death and after death, the family often gathers here to do their griefwork.

The chapel is on the groundfloor, in the center of the Hospice. It is spacious, bright and yet intimate and warm. The placement of the chapel in the center of the Hospice is symbolic, I think, of the place Christ and Religion take in the life of Cicely Saunders and the Hospice.

All grades of staff, volunteers, friends, visitors and especially the families of the patients, share in opportunities of

giving and receiving help in many ways. A friendly and peaceful atmosphere prevails.<sup>8</sup>

Volunteers contribute a great deal to the work of the Hospice, bringing in outside interests and lightening the task of the staff in many ways. There are over 100 volunteers and some 80 come into the Hospice each week. They are all ages and from all walks of life.

Cicely Saunders, the medical director, is a confessed Christian with the maturity of someone who has experienced failures and successes. She has the faith of a child. Her philosophy of life and her Theology is uncomplicated and clear and beautiful. In her I find faith and hope and love. The greatest of these is her love.

She writes about one of her patients, Louie: "For her faith was loving trust rather than belief in doctrine and concepts, in fact, it was hardly in words at all." This is true of Cicely Saunders herself. For her "faith gives substance to our hopes and makes us certain of realities we cannot see." For her faith is obedience to a command and she says that nothing can command us quite so inexorably as an inner conviction. It is in action that faith is seen, grows and develops. Faith is a gift of love, from love to love. Faith is "I know you—I trust you" and the symbol of faith is the gesture of the hands open to receive. We love because Christ first loved us, because His hands are open to us, and they have in them forever the prints of the nails.

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<sup>8</sup>Patricia Cumin Scott, Some Information For Those Caring For Patients (London: St. Christopher's Hospice, 1974), p. 1.

Cicely Saunders is touched by the suffering of the terminally ill. She believes that it is the Christian's task to relieve the trials of others where one can and to accept one's own when they come to one.

When Christ was facing death in the Garden of Gethsemane He said to His disciples, "Watch with me." This, she believes, is the attitude of mind and heart in which we must approach the dying so that we may try to learn from them and give to them. Where we are allowed to watch closely and to share deeply, we may not find an answer to all our questions about suffering and death; but instead, we find a PERSON and questioning is turned into wonder.

Cicely Saunders believes that the dying need the Community, its help and fellowship and the care and attention which will quieten their distress and fears and enable them to go peacefully. Cicely Saunders had managed to turn a Hospital into a Hospice into a Community into a family where people love because they are loved.

### 8.1.3 The Work in the Hospice

At St. Christopher's people suffering from cancer and long-term neurological illnesses are welcome at a time when everyone else has said: "There is nothing more we can do for you!" Cicely Saunders believes that this is never true. There is always something else that can be done for the patient and the family to support them and to make them more comfortable.

A social worker's report is required to accompany the application for admission to St. Christopher's. The human situation



behind the medical details is seen as crucial. The patient is seen as part of a family and everything that happens will affect each member. The family then, becomes the unit of caring.

New admissions to the Hospice are met in the ambulance by the matron or the assistant matron with a "welcome to St. Christopher's. We are glad to have you. We hope you will be happy." The patients are transferred from the ambulance into their beds and taken to their assigned ward. Friends and families are welcomed and encouraged to help whenever and wherever they wish. The patients and their families are seen on admission by a doctor who is prepared to spend time with them.

Not everyone who is admitted to St. Christopher's knows their diagnosis or prognosis and they have usually been given a variety of reasons for being transferred to St. Christopher's. Some of those admitted have been in contact with St. Christopher's through the domiciliary care service or have been attending the weekly clinic for consultation with the doctors. Others may come from other hospitals where they have felt unwanted and that no one has time for them. Sometimes they are very much rejected! Some have been told that they are going to a home where they can recuperate and can receive better care than on a busy acute ward. Some have reached the stage of acceptance where they are pleased to begin to let go and others are frightened and apprehensive.<sup>9</sup>

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<sup>9</sup>Galton, "Cancer Nursing . . . ," pp. 122-123.

Cicely Saunders<sup>10</sup> believes that every patient needs an explanation of his/her illness that will be understandable and convincing to him/her if she/he is to co-operate in his/her treatment or be relieved of the burden of unknown fears. This is true whether it is a question of giving a diagnosis in a hopeful situation or of confirming a poor prognosis.

It is only by waiting and listening that the medical team can gain an idea of what they should be saying. The real question is perhaps best expressed simply as "What you let your patient tell you?" With this philosophy patients at St. Christopher's who give clear signals that they are aware of their prognosis and ask for confirmation will be answered honestly and openly. Patients who need to deny the truth and signal "Hands off" will be supported and loved where they are and where they choose to be.

St. Christopher's is dedicated to a deep personal involvement with patients, and no heroic measures are taken to resuscitate a dying patient. Intravenous feeding poles and the like are not used. Through an intense effort by the staff for a human concern toward the dying, previously anxious and depressed patients frequently become relaxed, trusting and even serene, and they die peacefully and in dignity. The object of the staff effort is not to prolong dying, but to bring peace of mind and improved living for whatever time is available to the patient. The atmosphere in the hospice is one of

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<sup>10</sup>Cicely Saunders, "Telling Patients" (London: St. Christopher's Hospice), unpublished paper.

cheer and encouragement rather than one of depression. Family, children and volunteers are abundantly evident.<sup>11</sup>

Any member of the staff, or volunteer, may become involved in the patient's questionings. It will not always be possible to give a complete answer. Only the doctor and the senior nursing staff or the chaplain are in a position to do this, but whoever the patient has addressed her/his remarks to, that person must attend with empathy, not brushing aside the topic, but trying to discover what the patient's difficulty is so that the matter can be clearly and confidentially reported to those in authority. Significant remarks may be noted by anyone on a pink sheet in the patient's notes.<sup>12</sup>

The staff is encouraged to sit and talk to a patient when that is what the patient needs more than anything else in the world. Anyone may sit on the beds without feeling guilty when the matron walks in. At St. Christopher's, if a member of the staff, the chaplain or an orderly were seen sitting on a patient's bed, holding the patient's hand and talking to her/him, no matter how busy the ward might be, it would be understood and accepted that that was what had to be done at that moment. Never would one see someone standing while talking to a patient. (If one stands and talks down to a patient in a bed one has a psychological advantage over the patient.)<sup>13</sup>

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<sup>11</sup>Melvin J. Krant and Alan Sheldon, "The Dying Patient—Medicine's Responsibility," Journal of Thanatology, 1:1 (January-February 1971), 16.

<sup>12</sup>Scott, Some Information . . . , p. 1.

<sup>13</sup>B.J. McNulty, "Meeting the Problem of Communication in the

At least once a week the patient at St. Christopher's has the opportunity for a heart-to-heart talk with her/his doctor. She/he will be seen everyday by a doctor, but she/he can count on a special time to her/himself once a week, with no-one hovering near. The time need not be long; it is the quality of undivided attention that will count.

Nursing care is aimed at allowing the patient to maintain as much independence as is possible by imaginative care with great attention to detail and without rush. This means learning to listen and learning from the patients what their needs are—not what the staff think they are. It also means learning to feed a patient with patience and devotion—not with a mind straying on to other things. People will take what fluid and/or food they require given by another person; staff, chaplain or volunteer, and how much nicer this is than being fed through a tube.<sup>14</sup>

The aim is to relieve physical, mental and spiritual distress, so allowing patients time to come to grips with their own illness in their own time. Pain, nausea, vomiting, confusion and weariness can be controlled by the right use of narcotics, antiemetics, and anti-depressants. Adequate doses are used and given regularly at four hour intervals. At St. Christopher's the staff are experts on relieving

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Ward and in the Home," in Graham Bennette (ed.) Cancer Priorities (London: George and Chase, 1971), p. 65.

<sup>14</sup>Galton, "Cancer Nursing . . . ," p. 123.

pain.<sup>15</sup> The use of alcohol should not be underestimated, especially in the elderly. All the patients are offered an alcoholic drink once a day.

Visitors are welcome at any time, except on Monday, which is the visitors' day off. Relatives may stay at night at the bedside if the patient wishes, which is what most of them want to do, or else a room is made available to them. All who enter the Hospice are welcomed by the reception staff with a smile that says: "We are pleased to see you."

When a person is dying she/he is not hidden away. She/he dies in the bed and in the ward she/he became accustomed to, amongst the other patients who became friends. The other patients are allowed to be part of the caring. In this way they see what dying really is and that the caring goes on until the end.<sup>16</sup>

To do all this takes people. St. Christopher's has a higher ratio of staff to patients so that the staff do not get overtired and to ensure that they have free time and well spaced holidays. What is amazing is the fact that a bed at St. Christopher's is still cheaper than any other hospital bed from which the patients have come. In 1972/1973 when the cost per patient bed at St. Christopher's was £74 per week, the average cost for a week in a London teaching hospital was £129.<sup>17</sup>

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<sup>15</sup>Ibid., p. 122.

<sup>16</sup>Ibid., p. 123.

<sup>17</sup>St. Christopher's Newsletter #29.

The staff meets regularly in groups, discussing the patients, the problems, the work, their grief about someone very special who died and themselves.

At St. Christopher's suffering becomes tolerable because the family, the community of believers, the people are people who care and love. At St. Christopher's one experiences God and his love. Words are unnecessary. God is real. One continually sees that faith in God and His care is made infinitely easier by faith in someone who has shown kindness and empathy.

The Cross on the walls of the Hospice is an empty Cross. The hope that lives at St. Christopher's and in the heart of Cicely Saunders is not a hope that says that death is not there; It is a hope that says that death is there, but resurrection is at the other side of death. Hope, Faith and Love—This is what sustains Cicely Saunders and life at St. Christopher's.

#### 8.1.4 Anticipatory Grief

At St. Christopher's one of the underlying assumptions is that death is a fulfillment. Cicely Saunders says: "The last stages of life should not be seen as a defeat, but as a fulfillment." But to live and to grow while one is terminally ill is really not that easy. There is a lot of hard work to be done. One of the major things is the grieving for what one is losing; is to be able to disengage oneself from things and people; is to say good bye.

At St. Christopher's the patients are helped to do their anticipatory grief and to finish unfinished business. Invaluable to

this is the services of Dr. Colin Murray Parkes.<sup>18</sup> Dr. Parkes visits the patients regularly and he leads different patients' groups once a week. The group meetings are optional and open to all patients. They are free to discuss common concerns in the group. I will call these groups "anticipatory grief groups" because of the fact that grief work is being done in the groups and unfinished business is finished. The majority of patients are alert and able to join the group until perhaps a day or two or even a few hours before death.

The staff are sensitive to the needs of the patients in these regards. If a patient wants to say goodbye to a dog or a cat or a grandchild every effort is made to grant these requests. Often one would see a pet with the patient on the bed.

Once a month the Hospice has a social evening. The staff, family members and patients gather together in a relaxed atmosphere. Tea, coffee and alcoholic beverages are available. Family members who have lost loved ones return to the Hospice to converse with staff and the other patients. This gives them an opportunity to talk to the nurse or the doctor about the deceased, and aids them in their process of bereavement. Patients are able to observe how the Hospice takes care of the family even after the death of the loved one and find it consoling, assisting them in their anticipatory grief.

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<sup>18</sup>Dr. Parkes is the author of Bereavement (London: Tavistock, 1973) and numerous articles dealing with grief and bereavement.

#### 8.1.5 Domiciliary Care

When a patient is discharged from the hospice, care is taken that everyone involved clearly understands the situation. Nursing, medication and other needs are carefully explained to the family members, the family doctor and the district nurse. These periods at home may alternate between brief and extended.

The domiciliary care nurses of St. Christopher's visit the patient and the family at home quite frequently, maintain a watch over the patient's progress, give advice, support and supervision on drugs until readmission becomes necessary. This in-out-in shuttle is sometimes repeated several times during the course of an illness. The success of this rather complicated maneuver depends on good communication. Success is measured in terms of a family coping well in a crisis situation without undue anxiety, stress and distress for any member.

Nursing procedures are not as a rule undertaken by the Hospice nurses. This is the work of the District Nurse, but the Domiciliary Care nurses are very willing to help when help is needed and asked. The home situation is continuously evaluated to determine whether deterioration warrants hospitalization. In this way the family never feels abandoned and is assured that re-admission to the Hospice can be arranged at any time. The nurses that work in this program are those the patients have seen at the Hospice and in this way the link is maintained.



The home visits are leisurely and more time consuming. A point is made of talking to the patient and the family together and separately. The family are encouraged to talk about everything.<sup>19</sup>

The Home Care program forms a link between St. Christopher's and the community. The waiting list for admission is not an arbitrary thing of "Who is next in line?" but a flexible arrangement of "whose need is today the greatest?" More and more doctors are referring patients at an early stage, long before they need admission to the wards; to the Domiciliary Care program in order that they may benefit from the specialized knowledge and experience that St. Christopher's can offer in the control of terminal pain and distress, and so that they may get to know the people and the place where they will one day be cared for.

Many patients choose to die at home, in familiar surroundings, in the midst of their loved ones. This became possible with the introduction of the Domiciliary Care program. This is, without doubt, one of the most far-reaching developments of Hospice care!

## 8.2 Implications: How Can We Translate This Into the Modern Hospital

### 8.2.1 The Medical Team

During recent years with the miraculous achievements of modern medicine and the increasing specialization it became evident that no one profession or person can meet the total needs of a

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<sup>19</sup> McNulty, "Meeting the Problems . . . ," p. 63f.

patient and the family. Although we are dealing with one person the needs may be totally divergent and it will take a number of different persons with a variety of skills and training to assist a patient in meeting the different needs. This is especially amplified during the terminal phase of one's life.

William Easson regards every person who comes into contact with the terminally ill patient and who is concerned about the patient's welfare and comfort as a member of the team.<sup>20</sup> In most modern hospitals doctors and nurses realize that it does not serve the best interest of their patients to work in isolation. Therefore conscientious attempts are being made to merge members of the different professions. Because the patient is the center of attention and care and her/his welfare is considered first there is usually little problem in getting the cooperation of the members of the different professions. Gradually the doctor's role is that of the leader of the team, a co-ordinator of the efforts of nurses, pastors, physiotherapists, occupational therapists, social workers, laboratory technicians, radiographers, psychiatrists, speech and play therapists, etc.

I was struck by the importance and attention given to each person who works with the patient at St. Christopher's in London. Everyone is invited to share the way they experienced the patient during their interaction. Even the ambulance-men responsible for the

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<sup>20</sup>William Easson, The Dying Child (Springfield, IL: Thomas, 1972), p. 83.

transportation of the patient from another hospital to St. Christopher's are invited to sit down with a staff-member. Over a cup of coffee or tea they discuss their encounter with the patient and family. It is unbelievable how much can be learned about the patient and the family from them!

When getting together to discuss the patient, the members of the different professions usually discover that they are not far apart in their thinking. Robert Kastenbaum and Ruth Aisenberg<sup>21</sup> illustrate this by describing the independent reactions of a physician, psychiatrist, minister and a social psychologist to a case history of a terminally ill patient. There was general agreement among the above mentioned four members of the team that in the dying situation today:

1. We tend to impose emotional isolation upon the dying person.
2. We tend to treat him in a routinized manner.
3. We tend to treat him as though he were an irresponsible child, unable to cope with the situation on an adult level.
4. Among the people who were infinitely involved with the patient's well being the patterns of communication are inadequate and unreliable. This ranges from what the doctor says to the patient and how he says it, to all the little ways by which everybody withholds or misinterprets significant information.
5. There is a failure on the part of all persons involved to recognize and fulfill their share of the total responsibility.

Each member of the team has a special perspective on the care given to each patient and each member is responsible for a unique area of the treatment and therapeutic approach to the terminally ill patient. It is only through their combined efforts that total care

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<sup>21</sup>Robert Kastenbaum and Ruth Aisenberg, The Psychology of Death (New York: Springer, 1972), p. 218.

can be given to the "whole person," i.e., attending to the physical, psychological, spiritual and social needs of the patient.

The patient comes in contact with several different members of the team every day. When treatment plans are established each member must be involved and consulted for continuity to be established. Care plans, regular conferences and clear communications between members of the team are essential to provide optimum care to the terminally ill patient and the family.<sup>22</sup>

Without good co-ordination and regular conferences each member of the team will feel free to withdraw from the dying patient's needs, isolating the patient and the family and leaving them to struggle on their own. Another danger is that in any effort to serve the patient all members risk encroaching on the professional territory of the others.<sup>23</sup>

Throughout the history of the Christian Church the caring was devoted to the whole person; to the human being in her/his totality. The pastor, as a member of the team in the modern hospital is in an excellent position to continue the tradition. The pastor cannot and may not work in isolation. The hospital chaplain who is not a member of the medical team and acts on her/his own is doing a disfavor to the patient and has to reconsider her/his position and situation in

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<sup>22</sup>S. Stadnyk, "The Team Approach to Dying and Death," Journal of Thanatology, 1:5 (1971), 344-350.

<sup>23</sup>"Thanatology Looks at the Doctor and the Dying Patient," Medical World News (May 21, 1971), 34.

the hospital. Melvin Krant<sup>24</sup> believes that patients are comforted to know that the physician and the clergyman are working together and support each other as well as the patient. Being a member of the team the clergyman may find help, support and guidance in dealing with her/himself and the human issues at hand. The pastor can also render invaluable services to the team in helping them cope with their own anxieties and feelings of failure. A sensitive pastor who listens to the nurses and interns may very soon become aware of a tremendous need to talk about their own emotions and reactions to their work. This is especially the case on wards for the terminally ill. The pastor is in an excellent position to initiate a group for members of the team.

Elmer Laurson,<sup>25</sup> Protestant Chaplain at the University of California Medical Center, San Francisco, reports on such a group:

These meetings were begun at the request of the head nurse. When it became apparent to both of us that the nurses and nurses aides were badly shaken by the deaths of several patients in rapid succession, several of whom were rather young—from 14 to 30 years of age.

At first the nurses spoke of their feelings in rather guarded terms--without, in fact, allowing much emotion to be evident. As they became involved in hearing their feelings in the staff conferences they discovered that others in the group experienced similar emotions and they grew to accepting each other's and their own deep emotions. As a result, not only did they become freer and more open about death and grief, but they were able to become involved with their patients and the patients' relatives in helpful, purposeful relationships.

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<sup>24</sup>Krant and Sheldon, "The Dying Patient . . . ," p. 18.

<sup>25</sup>Elmer Laursen, "Chaplain-Nurse Relationship and Its Effect on Patient Care," in American Protestant Hospital Association, College of Chaplains Addresses and Workshop Papers (Chicago: 1969), pp. 102-105.

When the patients want to talk about dying or, on the other hand, wish to avoid or evade discussion of it, the nurses are able to go either route with poise and equanimity. Specific situations may be discussed in detail at the staff conferences. The nurses and aides request and receive counsel as to various aspects of the nurse-patient relationship, hang-ups and frustrations encountered, use of 'techniques' previously tried, meanings of verbal and non-verbal communication observed.

I may say very little during these group sessions and serve mainly as an 'enabler.' Occasionally it is necessary to ask a question that may help to point up specific dynamics or to make a clarifying statement. Advice is seldom offered. Basically, the main purpose of these weekly conferences is to assist the nurses and aides to become more aware of and to accept their own and each other's feelings and therefore become freer and more natural with their patients. Chaplain-nurse relationships have been deepened and the benefits to the patients are immeasurable.

Several months ago the physicians on the cancer research unit, including the residents, interns, and senior medical students, joined our weekly conference at their own request. Increasingly, the physicians have been willing to share their views of the patient as a person, the patient's physical and emotional needs, the physician's own hang-ups and needs in working with the critically ill and terminally ill patient and with the staff. Again, the benefits accruing to patients and staff from such free exchange are beyond measuring.

Only when caring is directed to the patient in her/his totality by the closely cooperating medical team can it be of therapeutic value to the terminally ill patient and the family.

#### 8.2.2. The Pastor Working With the Terminally Ill

Heije Faber<sup>26</sup> writes about the pastor in the modern hospital:

We might perhaps say that while the minister is formally accepted in the hospital, he is nevertheless not 'noticed,' and hence has no clearly defined place—often, in fact, he has no room or staff. This is partially, at any rate, because his work is little understood. For the minister himself this raises some significant

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<sup>26</sup>Heije Faber, Pastoral Care in the Modern Hospital (Philadelphia: Westminster Press, 1971), pp. xi-xii.

problems. He comes to realize that his place in the hospital rests on weak foundations; in the progressive secularization of society, which affects the hospital deeply, how long can he count on the place he has at present? He asks himself whether this place is perhaps his at present only because of a kind of 'guilt feeling' on the part of the medical staff, which is aware of its onesided relationship with patients. But, how long will this last? He realizes that he must clarify his place and role in the hospital both to himself and to the hospital staff, not only in order to keep his position, but in order to fulfill his task properly. In so doing he will also need to integrate his place and role into the whole complex of the staff through good contacts. Finally, to clarify is not all. He will also have to make his role credible . . . .

How can the pastor working with the terminally ill patient make his role credible?

In the modern hospital the pastor could easily be caught in the turmoil of rushing from day to day and from moment to moment. It is important that the pastor will be kind to her/himself and take care of her/his own spiritual needs. It is necessary that the pastor spend a sufficient amount of time by her/himself in prayer and meditation, cultivating her/his own personal faith, the resultant manifestations of which she/he is responsibly bound to pass on to the people in the hospital, under her/his care, if her/his ministry is to be in the fullest sense a Christian ministry. In very few other places and situations is one's own spiritual bankruptcy as clearly and easily exposed as in one's ministry to the terminally ill where one is confronted with life and death! On the other hand, ministering to the dying could start one off on one's own spiritual pilgrimage and one's life can take on new dimensions of depth and intensity. The patient is the very first one who will benefit from this!

Carlozzi<sup>27</sup> quotes R.J. Fairbanks as saying:

Continually ministry to the sick is an extremely debilitating experience . . . . It is important that we recharge our spiritual batteries from time to time. If this is not done the pastor fails in his responsibility to himself, for the man who is spiritually dry internally can offer nothing to those to whom he ministers, except, perhaps, his own despair, lack of trust in God's goodness, and the burden of his own personal inadequacies.

It is not until the pastor has become an "incarnate" instrument of God's love, however much internal wrestling and turmoil this may cause him, that he can truly be said to be carrying out an effective and responsible terminal ministry. Robert Buxbaum said.

Even God could not communicate His love until He did it in person—In the same way we cannot communicate the fulness of God's love until we become incarnate. We must all enter into relationships as persons of flesh, and as one patient said to me early in my training: 'Don't tell me how much God loves me, tell me how much you love me. Then I'll make up my mind about God.'<sup>28</sup>

Nobody can minister to her/his fellow women/men when she/he is unwilling to deny her/himself in order to create the space where God can do His work. How can we really be of help if we keep concentrating on ourselves? So the identity of the pastor, as it becomes visible in her/his pastoral care is born from the intangible tension between self-affirmation and self-denial, self-fulfillment and self-emptying, self-realization and self-sacrifice. There are periods in life when the emphasis is more on the one than on the other, but in general, it seems that as a person becomes more mature she/he will

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<sup>27</sup> Carl G. Carlozzi, Death and Contemporary Man (Grand Rapids: Eerdmans, 1968), p. 60.

<sup>28</sup> Ibid., p. 61.



become less concerned with girding him/herself and more willing to stretch out his/her hands and to follow Him who found His life by losing it.<sup>29</sup>

The pastor, at the very beginning, is in a paradoxical position, for she/he seeks to represent the Divine while being human, and would seek to give insight into the mysteries that are ultimately as mysterious to her/him as to others. She/he would speak of immortality while deeply aware of her/his own mortality. She/he would seek to explain the meaning of death when she/he has only conjectures and no final answers. The pastor is a human being, strong and weak, subject to temptation and doubt, misrepresentation and weariness as well as joy, love, hope and encouragement. She/he is man of God; with God and for God, which marks her/him out as intensely human, able to quicken the humanity of others.<sup>30</sup> In her/his relationship with the patient the pastor will make her/his own faith in the meaning of life available to the patient in order to allow the patient to find support to confirm or rediscover her/his own faith in life.<sup>31</sup> Margaretta Bowers et al.<sup>32</sup> says that the attitude of the pastor

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<sup>29</sup>Henri J. Nouwen, Creative Ministry (New York: Doubleday, 1971), p. 47ff.

<sup>30</sup>James R. Mathers, "The Pastoral Role: A Psychiatrist's View," in M.A.H. Melinsky (ed.) Religion and Medicine (London: S.C.M. Press, 1973), II, 91-92.

<sup>31</sup>Paul Sporken, De Laaste Sevensfase (Bilthoven: Amboboeken, 1972), p. 84.

<sup>32</sup>Margaretta K. Bowers et al. Counseling the Dying (London: Nelson, 1964), p. 63.

towards death will have much to do with the way in which she/he ministers to the terminally ill patient.

I believe that a prerequisite for any ministry to the dying is that the pastor should think through her/his own feelings about death. I doubt whether one can work entirely through one's feelings about death. Thinking it through would help the pastor not to avoid the issue. When the pastor avoids her/his own finiteness, then she/he will also avoid symbols and signs of it, out there—in the patient. People will not open up to the pastor about any area that the pastor is closed to in her/his own person. The patient will sense which areas in their relationship is "verboden" and she/he will not trespass onto areas that she/he senses the pastor to be judgmental about, or closed to, or afraid of. The more the pastor is able to grow in this regard, the more things the pastor allows her/himself to deal with in her/his own experience, the wider and broader and more open people and in her/his case, the terminally ill patient, will be with the pastor. The impasse in a relationship has to do as much with the pastor as with the patient!

Competency comes partly from learning new skills, information and knowledge, but more important than these is the pastor's own personal growth, maturity, integrity, openness, and willingness not to avoid but to deal with more areas of life and with reality.

A way in which the pastor can in some way prepare her/himself emotionally for the experiences of death, dying and grief is the willingness to look at the reality of her/his own death in an open

manner and accept the full emotional impact of this experience into her/his own present being.

One beginning checkpoint would be to engage in a detailed fantasy of one's own dying and death, then seek to imagine what it would be like not to be, to picture in one's mind the world simply going on without her/him. If a person finds her/himself totally unable to go through such a fantasy in some detail with some degree of reality and emotional response, it may well be that her/his own feelings about death, her/his own awareness of her/himself as a mortal human being, have been too well repressed. An opposite reaction is also possible. In the midst of such fantasy a person begins to find her/himself overwhelmed by emotion; anxiety rises too strongly; the feelings block the progress of the fantasy or linger on well after the fantasy is concluded or she/he cannot get her/his mind off death. In either instance, the pastor would be well served as a person and as a professional if she/he were to talk this over in detail with a competent and sensitive colleague or with some other professional counselor.<sup>33</sup>

Clinical Pastoral Education provides an excellent opportunity to work on one's feelings in the safety of a support group, under competent leadership.

At times the pastor working with terminally ill patients may get very involved in a patient—especially in cases where the

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<sup>33</sup>David K. Switzer, The Minister As Crisis Counselor (New York: Abingdon Press, 1974), pp. 137-138.

relationship has grown and matured. The pastor may find her/himself with unresolved feelings when the patient finally dies. It may be crucial for the pastor to work on her/his feelings in the safety of a support group or in personal therapy. It is necessary to finish unfinished business before one would be entirely free to move into a new relationship with another terminally ill patient.

When I was working at St. Christopher's in London a much loved patient, M., who had been in the Hospice for many months, died. The staff were very sad, but supported each other beautifully through physical contact and talking about what happened. The day after the death of M. while I was climbing up the stairs I saw Dr. Cicely Saunders, the medical director, coming from the basement where I knew, the Hospice's mortuary was. I waited for Dr. Saunders and while we were walking, she said:

I was not present when M. died yesterday. I was so busy that I couldn't go down before this evening. I knew M. for a long time and I loved her a great deal. She was such a beautiful person. I went down to see her body and to finish my unfinished business with her.

Dr. Saunders' eyes were wet, but she was ready to go on with her task and responsibilities!

I have learned that when one's mind is preoccupied with personal problems and personal anxiety that it is humanly impossible to be completely with a terminally ill patient and attend to her/his needs. I remember one day when my little boy was seriously ill at home. While I was physically with the patient my heart and mind was at home where I knew my wife was struggling with him. I was embarrassed when a terminally ill patient asked me what was on my mind

and told me to do what is most important to me. I went home. After that there was fortunately enough, still enough time to be with my sensitive loving terminally ill patient!

The pastor does not have any medical or technological functions to perform. Kastenbaum<sup>34</sup> agrees with Robert Buxbaum when he says: "On the most significant level the (adequate) minister doesn't do anything in the sickroom. He has not come to see the patient. He has not come to treat the patient; He has not come to perform any magical rites. He has come to be with the patient; Simply that."

Kastenbaum observes that in mobile and achievement oriented cultures where emphasis is on performance and productivity it may require a high degree of self-confidence and inner tranquility for the minister simply to be with the patient! There is no assurance that most hospital personnel are psychologically capable of being with the terminally ill patient and the family. The "busyness" of the staff may serve to avoid deep interpersonal contact with the patient and the family. The pastor is in a unique position to be helpful in a distinctive way, that other members of the team cannot! The positive presence of the clergy with the terminally ill patient can reduce the staff's insecurity and guilt about the fact that the patient is dying and there is "nothing they can do." The hospital personnel needs this counterbalancing orientation.

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<sup>34</sup> Kastenbaum and Aisenberg, The Psychology of Death, p. 227.

The fallacy is the belief that every pastor has acquired enough "common sense" psychology and knows her/himself well enough to enable her/him to deal with terminally ill patients' psychological or personality problems. It is not possible to care adequately for the terminally ill patient without training in Clinical Pastoral Education, group dynamics, and personal therapy.

The pastor should know her/his own limitations. When she/he finds that she/he has run into a problem which is too big for her/him to handle, she/he must turn it over to a more skilled and experienced counselor. The patient will appreciate the honesty and still trust the pastor.

Carlozzi<sup>35</sup> says that one of the problems causing much frustration in the pastor in working with the terminally ill is the fact that patients cannot communicate or think clearly and the pastor finds her/himself in a position in which she/he must carry a running monologue with her/his own inner self. My own experience is that if pain is kept under control and the patient is comfortable the majority stay alert and active (especially verbal) until very close to the end.

To be helpful the pastor must communicate understanding, love and faith with a great deal of guidance of the Holy Spirit.<sup>36</sup> Pastoral ministry to the terminally ill patient is therefore pastoral

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<sup>35</sup>Carlozzi, Death and Contemporary Man, p. 57.

<sup>36</sup>Carl J. Scherzer, Ministering to the Dying (Philadelphia: Fortress Press, 1963), p. 45.

solidarity with the other, supporting her/him in the quest to become one who dares to believe in her/himself, because she/he has discovered through the pastor, experienced through her/him, that Christ believes in her/him.<sup>37</sup>

#### 8.2.2.1 The Clinical Trained Chaplain

The hospital chaplain is working essentially with persons she/he has never met before hospitalization, and with many who do not accord her/him the pastoral authority which parishioners give their pastor. During the past few years denominational differences have become less significant; hence the hospital chaplain will to a considerable extent represent the "church" and "God." What she/he can immediately share with patients is a participation in their human anguish, but not always in their religious structures, since it will take time to discover what those are.<sup>38</sup>

The chaplain feels comfortable and at ease in the hospital. The hospital is her/his parish. She/he knows the building and she/he knows the members of the team after some time. The patient brings her/him together with the other members of the team and determines the relationship to one another, helps the members of the team to listen

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<sup>37</sup> Faber, Pastoral Care in the Modern Hospital, p. 90.

<sup>38</sup> Lawrence E. Holst, "The Hospital Chaplain and the Parish Pastor," in Lawrence E. Holst and Harold P. Kurtz, Toward a Creative Chaplaincy (Springfield, IL: Thomas, 1973), pp. 105-111.

and to pay attention to each other. The pastor's place in the team will be determined by the needs of the patient, by her/his contribution to the patient's well-being, and always seeks to establish, where necessary with others involved, where her/his care for the sick fits in best with the care of others.<sup>39</sup> The pastor and the other members of the team meet regularly around a conference table in an interdisciplinary setting. The team are committed to help the patient achieve an emotional world in which to die.<sup>40</sup>

When the pastor starts working in a hospital on a full-time basis she/he will have to take the initiative to reach out to the staff; to get acquainted and to demonstrate her/his usefulness. Even though this may take some time it will be time well invested and the pastor and the patient will benefit tremendously. The pastor-chaplain may be involved in Clinical Pastoral education and organize workshops and symposia from time to time on relevant issues. This may aid ministers in understanding themselves and the needs of the terminally ill.

#### 8.2.2.2 The Parish Minister

The parish minister going to the hospital to visit a parishioner usually feels out of depth and out of place. Her/his visit

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<sup>39</sup>Faber, Pastoral Care in the Modern Hospital, p. 74.

<sup>40</sup>Ruth D. Abrams, "The Patient With Cancer—His Changing Pattern of Communication," New England Journal of Medicine, CCLXXIV (February 10, 1966), 317-322.



may be at an inconvenient time. She/he uses her/his clerical clothing to enter the hospital and usually does not ask for permission to visit. The nurses feel uncomfortable with her/his presence. They do not know her/him and do not know what to expect from her/him.<sup>41</sup>

The pastor usually knows something about the hospitalized parishioner. Most of the times she/he has had a prior relationship with her/him. She/he most likely knows something about the attitudes, values and religious structures of her/his parishioner-patient, who is accustomed to seeing her/his pastor active in certain religious rituals, such as conducting worship, preaching, praying and distributing the elements of Holy Communion.

The parish minister quickly realizes her/his limitations. She/he realizes that her/his prior relationship with the parish-parishioner is overrated. She/he realizes that the experience of illness has almost rendered the patient a stranger to her/him.

The parish pastor also feels less accessibility to her/his parishioner-patient during the period of hospitalization. Unlike the chaplain who is in the hospital all day she/he spends only a small portion of her/his day there. Sometimes she/he visits the hospital only once a week.<sup>42</sup>

During the past years I have closely watched the behavior of parish-ministers coming to the hospital. First of all I was struct

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<sup>41</sup>Faber, Pastoral Care in the Modern Hospital, p. 70.

<sup>42</sup>Holst, "The Hospital Chaplain . . . ," pp. 108-111.

by the visible uneasiness. During the visit the pastor seemed anxious and uncomfortable, frequently glancing at her/his watch. Usually their stay was of short duration. When the pastor was gone the parishioners would make remarks like: "He is such a fine man," "He is such a beautiful person." It seems to me that the majority of these calls served the purpose of bringing the local church into the hospital, extending the caring of the community of believers; Telling the patient that she/he is still in the thoughts and minds of the congregation. This was much appreciated, but in cases where the patient wanted to do some work, complete some incomplete gestalts, the hospital chaplain was chosen to work with, knowing that the hospital chaplain is accepted in the hospital, a member of the team and daily available within a few minutes.

The parish minister cannot be a member of the team in the hospital, attending patient conferences and discussions. Therefore it is very important that the parish minister work in close collaboration with the hospital chaplain who has access. This serves the patient and the family. The parish minister may be a valuable source of information to the team. She/he knows the patient's family and will hopefully visit them at home during the hospitalization. Families may abandon the patient when the patient becomes comatose. The staff may become distraught if the family does not appear. The possible reasons for the family's behavior must be discussed to help the staff become less hostile towards the family, for the families usually need more help and understanding. The parish pastor may provide the necessary information. The staff's attitudes are quickly picked up

by other patients and unless these feelings are worked out among the staff little beneficial can result.

The parish pastor often feels the lack of special training in sick visitation. Rarely does she/he have an opportunity—and in some cases a willingness—to submit her/his pastoral care of individuals to the scrutiny of her/his colleagues or specialists in the field that will enable her/him to grow in her/his interpersonal effectiveness.<sup>43</sup>

The parish-pastor will be wise to be sensitive to the atmosphere and unwritten rules of the hospital. Her/his clerical attire does not make her/him a special person with special rights and privileges. It is most important not to enter a ward without seeking the permission of the head nurse. She/he will usually find the nursing staff very open and helpful once they know her/him. To be friendly with the nurses and willing to listen to them too, will open many doors for the parish-pastor. If the parish-pastor is truly concerned about a patient and the family she/he may contact the doctor in charge and ask for an opportunity to discuss the situation. Most doctors are open to it and willing to engage the parish-pastor in the comprehensive care plan of the patient and the family. Especially in smaller communities where there are no full-time hospital chaplains in the hospital, the parish-pastor could fill the vacant position in the team. It is important though that the parish-pastor will remember that she/he has to take the initiative and make her/himself

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<sup>43</sup>Ibid., pp. 111.

available. In almost every situation I know of, the doctor appreciated the minister's interest and willingness to co-operate and excellent relationships were established between clergy and doctors.

### 8.3 The Therapeutic Use of Groups in the Modern Hospital

Much of the literature on Death and Dying focuses on the experience of patients and their families as they face the problem of death and dying. Included in this literature is the secondary aspect of the feelings, reactions, and insights of those who treat and minister to the terminally ill. But little has been written about methods of helping and sustaining dying patients and their families.

I have pointed out that the family member actually has no place in the modern hospital. Neither they as persons, nor their needs are considered as important. Most often they are seen as being in the way of the highly efficient medical team. Family members have to spend hours in waiting rooms; they have to grieve in corridors outside the patient's room; they are allowed five minutes in every hour at the bedside of a loved one in an Intensive Care Unit. The tendency is to treat the patient as an object. She/he has to let her/himself be treated and she/he is entirely dependent upon decisions made for her/him about her/him by others.

Looking at the hospital in this way we can understand why small groups are still not widely used therapeutically. Until very recently only the physical problems of the patient were considered as important and the emotional needs of the patient and the family were

totally ignored. Small groups, whether a growth or a therapy group focus on another dimension of the patient and family which is sadly neglected.

I believe that the pastor can minister to terminally ill patients and their families through individual contact, but many of their needs can be met through the use of growth groups. In this way the pastor can most effectively use her/his energy and personal resources. In the small sharing group lies the power which enables people to love more fully and live more creatively. This is the people dynamic—the power we have to recreate each other and ourselves through caring and sharing. Growth groups offer a means of releasing the people dynamic to help humanize personal relationships and to help create a world in which every person will have the opportunity to develop her/his full, unique capacities.<sup>44</sup> This is the therapeutic goal towards which the pastor, the patient and the client strives; to love more fully and live more creatively until the patient dies; to be in touch with her/himself; to be in touch with the family; to be in touch with her/his God.

Groups may be used effectively with terminally ill children. Though the pastor of a local parish may find this impractical if not impossible to develop her/himself, the hospital chaplains may be encouraged to use group techniques with children six and older in the hospital. A ward, sun room, or therapy room presents natural

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<sup>44</sup>Howard J. Clinebell, Jr., The People Dynamic (New York: Harper & Row, 1972), p. viii.

opportunities for group work.<sup>45</sup> With the help of a play therapist (study in this area may provide the pastor with valuable therapeutic resources) a playgroup can be introduced which would assist the terminally ill child in the task of anticipatory mourning, the task of maintaining a sense of mastery and of dealing with helplessness, guilt and anger and the child's task of maintaining the integrity and her/his identity, and the family's task of maintaining its integrity and cohesiveness.<sup>46</sup>

A couple's support group can be formed in cases where malignant diseases were diagnosed in one of the spouses, where surgery was done and chemotherapy and radiotherapy are used. It is almost impossible to really understand what people, being struck with cancer, are going through. These people can be brought together through the initiative of the hospital chaplain with the help and support of other members of the team. They can best minister to their own needs and each other's needs with the help of a skilled groupleader. They can become their own caring community which they need so desperately.

A parent's sharing or support group can be designed to help parents of children suffering from a terminal illness cope with some of the human threats that accompany the diagnosis, treatment and hospitalization and eventually death. In all the cases the agenda

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<sup>45</sup>James E. Kilgore, Pastoral Care of the Hospitalized Child (New York: Exposition Press, 1968), p. 27.

<sup>46</sup>Irwin Hoffman and Edward Futterman, "Coping With Waiting," Comprehensive Psychiatry, XX:1 (1971), 79.

will be wide open. Any topic of concern can and is encouraged to be shared. There are, of course, no right or wrong answers, and although various aspects of religion may be discussed there will be no attempt to impose an explicit value or religious system on the group.<sup>47</sup>

An anticipatory grief group can be developed for terminally ill patients and a separate group for their families. The family anticipatory grief group could become a grief recovery group after the death of a loved one. It is unbelievable how much deposits of unfinished grief reside in many hearts. In the intimacy of a small sharing group people can work through their feelings about their anticipated loss and after the death can experience the healing that will come. Unless people have the kind of help in dealing with their (anticipated) grief which is available in a sharing group, many patients will die with unfinished business and with no peace in their hearts, and family members will not experience the healing of their grief wounds.<sup>48</sup>

With some imagination groups can be developed to meet many different needs of patients and families that come to the attention of the pastor in the hospital. The first step in the planning and

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<sup>47</sup>LeRoy G. Kerney, "The Ministry and a Parents Sharing Group," in Bernard Schoenberg (ed.) Anticipatory Grief (New York: Columbia University Press, 1974), pp. 315-319.

<sup>48</sup>Howard J. Clinebell, "How to Set Up and Lead a Grief Recovery Group" (unpublished paper, Claremont, School of Theology, 1975). See Appendix B.

development of groups in a hospital is the approval and understanding of the medical staff. Without the sanction of the administration and the involvement of the treating physician and other members of the team there is little hope for a successful program.

#### 8.4 The Congregation—A Therapeutic Community in the Caring of the Terminally Ill Patient and the Family

Pastoral care lies at the very heart of the Christian Ministry. The whole Christian community should share in the chaplain's caring, for pastoral care is the concern of the church, both priest and laity.

The Church as the Body of Christ is at work in and through the chaplain, for she/he is in the hospital not as an individual but as a representative of that Christian community and is always acting on behalf of the congregation.

According to Willem Berger<sup>49</sup> pastoral care of the terminally ill patient is in the second place the task of the professional pastor. First of all, the terminally ill patient and the family are the caring responsibility of the community of believers, the congregation, to which the patient belongs. The church can only function optimally when it recognizes the variety of gifts within the individuals,<sup>50</sup> the latent potential that is available, and when it reminds

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<sup>49</sup>W.J. Berger, "De Pastorale Begeleiding Van De Terminale Patient," in F.J.A. Huygen et al., Menswaardig Sterven (Bilthoven, Amboboeken, 1974), p. 42.

<sup>50</sup>1Cor. 7:7.



the Believers, the members of the Body of Christ, of their own priesthood and eventually stimulate them to exercise it.<sup>51,52</sup> The whole congregation should therefore share in the pastoral care of the terminally ill patient and the family. It will then be fulfilling its vocation as a healing and caring fellowship, the very Body of Christ.<sup>53</sup>

It became more and more evident to me that with the increase of long term terminally ill patients, kept alive through modern medicine, that the pastor and her/his staff in the hospital are physically unable to care adequately for the terminally ill patient and the family. It is therefore crucial that the pastor will use, stimulate and activate the vast resource of lay people that are available. In this way much of the over-professionalism of the pastor will be submerged into a doctor-clergy-congregation partnership.

The family is the primary group for close, supporting and healing fellowships. But in the case of the terminal illness the family is just as involved as the patient and is in need of loving care and attention. In a small community the family is automatically surrounded by the healing ministry of friends. But in our secularized mobile societies, communities where this is still the case become increasingly limited. In a city, the people living next door may not

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<sup>51</sup>Math. 20:28.

<sup>52</sup>J.G. Straver, Zieken Thuis (Bilthoven: Amboboeken, 1972), p. 132ff.

<sup>53</sup>Norman Autton, Pastoral Care In Hospitals (London: S.P.C.K., 1968), p. 15.

even be aware of the fact that a member of the family is terminally ill.

Cicely Saunders<sup>54</sup> writes:

The dying needs the community, its help and fellowship and the care and attention which will quicken their distress and fears and enable them to go peacefully . . . . The community of the Church has a particular responsibility, not only to meet with people dying in many different surroundings and to sustain those who sometimes have to endure in very difficult places . . . . For most, the ideal is that they should die in their own homes, but so often this proves to be an impossibility . . . .

The pastor in the hospital could co-ordinate and train a lay people's caring group with the help and support of parish pastors and congregations in the community.

The pastor would, as part of her/his work in the hospital, come in contact with terminally ill patients and their families. In most cases there will be periods of remission when the patient is discharged to go home. In such cases the local parish pastor and her/his lay people's team must be notified whether the patient and her/his family are members of the church or not. Members of the group can visit the family, estimate the immediate needs and offer their services. In cases of extended terminal illness help at home with shopping, babysitting, cleaning, washing, cooking and at times just relieve the family of their responsibilities, to relax for a day or an evening.

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<sup>54</sup>Cicely Saunders, "And From Sudden Death," Frontier (Winter, 1961)

When the pastor is accepted in the hospital and regarded as a member of the team she/he could involve the nursing staff who are intimately working with the terminally ill patient and the family to determine the needs of the family. The head nurse could be asked to fill out a questionnaire<sup>55</sup> about the family. With this information, and her/his own knowledge about the family, the pastor could alert the parish pastor and the lay people's caring group.

Notwithstanding the limitations imposed by bodily weakness and incapacity an atmosphere of caring concern can transform the last stages of life from an occasion of failure and defeat into an opportunity for positive achievement and life's final fulfillment. This can only happen if the whole community supports the family and the patient with loving care and concern.

Many patients come from out of state or from surrounding towns and cities to many of the big teaching hospitals where more medical services are available. Thus, not only does the family have a terminally ill loved one to worry about, but they are alone in a strange city. They will soon become acquainted with the hospital chaplain and the chaplaincy staff. The caring team of lay people in the area where they stay during this time could be alerted and they can render invaluable services and provide a loving support group for the family during their time of trial.

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<sup>55</sup> See Appendix C.

There are hospitals where lay people are being used to do odd jobs for the terminally ill patient in the hospital—like writing letters, taking care of the patient's personal laundry, etc. Patients who are lonely and isolated may receive flowers or fruit from the caring group. Minna Field<sup>56</sup> describes a hospital where a group of lay people spend time with hospitalized children. Especially children who are isolated, have few visitors, are immobilized or present feeding difficulties will benefit greatly.

There are numerous possibilities of employing lay people in the caring team. The patient, the family, the pastor and the community will not only benefit through such a program but will grow emotionally and spiritually.

#### 8.5 Dying, Growth and Fulfillment

Humankind is limited, finite, a child of nature. She/he is constituted by and is subject to the laws, vicissitudes, and necessities of the natural order of existence. She/he becomes ill, she/he can tolerate only certain variations in the supply of heat, food, and oxygen, and she/he is an unrelieved prisoner of eventual death and decay. But humankind is an unrelieved prisoner of eventual death and decay. But humankind is also unlimited, infinite, a spirit. She/he possesses the ability to transcend him/herself and to make his/her ego both subject and object. His/her mind can move back and forth in

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<sup>56</sup>Minna Field, Patients Are People (New York: Columbia University Press, 1967), p. 61.

the dimensions of time and space, she/he can put him/herself into the world of another person, and she/he can anticipate the fact of his/her demise and can even imagine its possible circumstances.<sup>57</sup>

A person always lives in the conscious or unconscious anxiety of having to die. Non-being is present in every moment of one's being. The vicissitudes of existence threaten one from all sides. Suffering, accidents, disease, loss of relations to nature and people, loneliness, insecurity, weakness, and error are always with one. Finally the threat of having to die will become the reality of death.<sup>58</sup>

A person has the innate potential to grow, to mature not only physically but also emotionally from birth to old age. Many factors determine how much of this potential one realizes in one's lifetime.

Death is the end of life and as such the end of growth, or does the ego lose the faculty of growth when the person becomes terminally ill and the decay of the body starts? Or is the ego in a certain sense provided with a seemingly infinite potentiality of growth?

It is as if the scientific literature—as well as those who come in contact with the terminally ill patients pronounce the individuals psychologically dead before they expire.<sup>59</sup> Physicians and

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<sup>57</sup>Leroy Aden, "Pastoral Counseling As Christian Perspective," in Peter Homans, The Dialogue Between Theology and Psychology (Chicago: University of Chicago Press, 1969), III, 176.

<sup>58</sup>Paul Tillich, "The Theology of Pastoral Care" (Unpublished paper), p. 3.

<sup>59</sup>Joseph C. Zinker and Stephen L. Fink, "The Possibility For

nurses and other members of the team--as well as families of dying individuals have the tendency to distance themselves psychologically from the individual when the diagnosis of terminal illness is made. This may be a gradual process which reaches its culmination when the family (and even members of the team) complete their anticipatory grieving. Physical and emotional isolation of the patient makes dying an ordeal and leaves the person's life incomplete; unfulfilled!

The fact of the matter, however, is that great literary works, autobiographies, and news media have reported and described time and time again how individuals on the brink of death, or individuals who knew they were to die in the near future experience the greatest insights, the greatest joys, and important re-evaluations of their past lives. Many of these individuals achieve greater religious strength, greater love for their fellow man, find integration and closure of their past lives and sometimes grow and experience a sense of fulfillment.<sup>60</sup> Joseph Zinker and Stephen Fink<sup>61</sup> quoted Feifel who stated regarding the possibility of growth in a dying person:

Speaking of new information, it is encouraging to note that the threat of death can function as an integrative rather than necessarily disruptive event for certain individuals. One can learn, apparently, not only to adjust to inordinate stress, but to grow and change under its spur.

Do we encourage and stimulate growth in a terminally ill patient?

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Psychological Growth In a Dying Person," Journal of General Psychology, LXXIV (1966), 185.

<sup>60</sup> Ibid., p. 186.

<sup>61</sup> Ibid.

Faber concludes that there are many factors in a modern hospital which tend to make the patient weak and thus encourage regression towards infantile behavior patterns.<sup>62</sup> Aronson emphasizes the dehumanizing aspect of illness. The doctors, hospital, relatives set the stage for regression and dependency in a fashion, sometimes so tempting, sometimes so forceful that the ill patient is bothered far more by her/his guilt and shame in yielding to the regressive temptations than she/he is by pain or illness.<sup>63</sup>

It is important to remember that the terminally ill patient is a human being with the capacity to express the entire range of human needs. She/he is a living person and whether she/he has the opportunity really to live will be determined to a great extent by the milieu and the people around her/him. Death need not be an unrelieved calamity. Sometimes, of course, it appals us with its cutting short of a promising life. Often it comes as the culmination or coronation of a life well lived. In such circumstances, it seems wasteful, if not almost cruel, not to allow or to help and support the person to summarize, to take stock of the past, to express love and affection for those who will remain to carry on the living of life when this

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<sup>62</sup>Faber, Pastoral Care in the Modern Hospital, p. 63.

<sup>63</sup>Gerald J. Aronson, "Treatment of the Dying Person," in Herman Feifel (ed.) The Meaning of Death (New York: McGraw-Hill, 1965), pp. 251-252.

one steps out into a new dimension. Indeed, some of the most significant living can be lived in the shadow of the imminence of death.<sup>64</sup>

It is important, then, to help the terminally ill patient move toward her/his own inner nature, her/his full realization of positive resources available to her/him, her/his own potential as a person. We can do this by helping the patient to find and accept her/his own being and path; to sing her/his own individual song; to play in life the special music of her/his unique personality. As she/he moves in this direction there will be more acceptance and peace, even though she/he may deteriorate physically.<sup>65</sup>

Cicely Saunders<sup>66</sup> writes about a friend of hers who died when she was only forty years old.

The incredible thing is, you don't even feel sorry for her: she is so alive! Her dying had become the very means of her growth, for we learned from her husband that her intense aliveness gaiety and interest in other people had developed during her illness . . . . The less her body could do, the more her spirit shone, in love and amusement and a clear-sighted wisdom concerning life and those she met . . . . While she was ill she found faith in God, reaching out trustfully at first to what she saw dimly as true and finding that this constantly became clearer, more secure and more personal.

Thus, we see, that the terminally ill patient needs help in terms of how to live, help to tackle the deep problems of how to make the most

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<sup>64</sup>Donald Beatty, "Shall We Talk About Death," Pastoral Psychology, VI (February 1955), 13.

<sup>65</sup>Bowers, Counseling the Dying, pp. 81-82.

<sup>66</sup>Cicely Saunders, "Dimensions of Death," in Melinsky, Religion and Medicine, I, 114.



of her/his being. She/he needs help with questions of her/his existence that she/he has been unable to answer in a satisfactory way. The patient needs support in her/his search for his/her own inner strengths, to utilize them to the fullest, to help her/him cope and grow until the very end.

This approach makes far more sense to the patients than does a therapy attitude which concentrates on the search for psychopathology and its causes. It gives the patient much more self-respect, strength and hope. It may not be a hope for physical improvement, rather hope for that spiritual improvement which Maslow refers to as "self-actualization." This is the patient's real concern for her/himself; the core of her/his being.<sup>67</sup>

Tillich claims that the patient can only bear with the threat of her/his impending death in the power of that in which non-being is eternally conquered—the power of the Divine.<sup>68</sup> It has been my personal experience and it is reported by many people,<sup>69,70</sup> that there is a renewed interest in the power and therapy of religious faith during the terminal phase of a person's life. People look for the

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<sup>67</sup>Bowers, Counseling the Dying, p. 82.

<sup>68</sup>Tillich, "The Theology of Pastoral Care," p. 3.

<sup>69</sup>Doloris D. Boots, "Helping the Cancer Patient: The Minister and the Social Worker," Pastoral Psychology, XXII (January 1971)

<sup>70</sup>Clarence McConkey, When Cancer Comes (Philadelphia: Westminster Press, 1974), p. 105.

comfort of a personal God who is interested in them and who will help them during this time of crisis and stress.

"Our turn to religion is as natural and as genuine as the flight of the brown bird to the thicket."<sup>71</sup> This may be the reason why Lamerton states explicitly: "The clergyman is the member of the team, most suited for counseling the dying."<sup>72</sup> And Ruth Abrams:<sup>73</sup>

Religious faith added comfort and support to many patients and should be considered in any program for optimum management, especially in the terminal stage. Regular visits by the chaplain were of inestimable value to several patients. They were especially effective when the medical personnel and the clergyman were partners in treatment.

The research of Elizabeth Kübler-Ross<sup>74</sup> indicates a different trend:

Religious patients seemed to differ little from those without a religion. The difference may be hard to determine, since we have not clearly defined what we mean by a religious person. We can say here, however, that we found very few truly religious people with an intrinsic faith. Those few have been helped by their faith and are best comparable with those few patients who were true atheists. The majority of patients were in between, with some form of religious belief, but not enough to relieve them of conflict and fear.

As a psychiatrist of the Freudian school Elizabeth Kübler-Ross was most probably not specifically interested in religion. She admits her difficulty in defining a "religious person." I believe that people

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<sup>71</sup>Ibid.

<sup>72</sup>Richard Lamerton, Care of the Dying (London: Priory Press, 1973), p. 140.

<sup>73</sup>Abrams, "The Patient With Cancer . . . ," p. 321.

<sup>74</sup>Elizabeth Kübler-Ross, On Death and Dying (New York: Macmillan, 1969), pp. 265-266.

will not open up to me about any area that I am closed to in my own person. This may be the reason for Elizabeth Kübler-Ross's experience about religion. Reading On Death and Dying one becomes aware of the insignificant role that Chaplain Nighwonger played during the interviews she had with the terminally ill patients. Although Chaplain Nighwonger was present during the interviews Kübler-Ross monopolized the patient's attention totally.

As pastoral counseling attends to the problem of finitude (however it is expressed by the client), its goal is to help the individual move toward a Christian resolution of that problem. The resolution lies in the existential disposition of courage, and its meaning can be stated in Tillichian terms. Courage refers to the "self-affirmation of being in spite of the fact of nonbeing." because one is in "the state of being grasped by the power of being-itself." Therefore, pastoral counseling seeks to help the client move toward the ability to affirm his/her life in the face of its limitations, because she/he is rooted and grounded in the source and sustainer of life, namely God.<sup>75</sup>

Margareta Bowers<sup>76</sup> sees the task of the pastor as "helping to release the patient from the burden of guilt and the stress of anxiety. She/he can help the process of true self-discovery and self-actualization that can aid the person in being able to say with

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<sup>75</sup> Aden, "Pastoral Counseling as Christian Perspective," p. 177.

<sup>76</sup> Bowers, Counseling the Dying, p. 145.

illumination of spirit "I am." If there is ever the need for "the courage to be" it is at the moment when the prospect of non-being is encountered. The achievement of religious selfhood is not so much a matter of reason as it is of feeling, but wise guidance and counsel can help to achieve it."

The pastor can assist the terminally ill patient in his/her process of anticipatory grief. The patient may mourn about losing parts of his body or friends or relationships, etc., just as a loved one is mourned at death. When mourning is accomplished and the loss is an accepted fact, there is a bursting release of the psychic energy which had been attached to the infantile objects. The result is new energy which may emerge upon one as joy. The patient will experience this joy as growth and a movement to fulfillment.<sup>77</sup>

With the help of the team and the family the patient can experience love and caring and a sense of his/her infinite worth. She/he may be able to share it with his/her loved ones. With the help of the pastor she/he may be able to accept his/her finitude and God's acceptance of him/herself. This may lead to a new relationship with God.

Religious growth occurs when a person, searching for an authentic relation with God, finds himself, and his/her neighbor and

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<sup>77</sup>George Benson, "Death and Dying: A Psychoanalytic Perspective," Hospital Progress LIII (March 1972)

his/her community. Growth cannot occur in isolation; only through contact and community.<sup>78</sup>

We must pray that we will be able to make it possible for the patients to pack their bags with the right things, pack them with what matters, with what they need; that while they are in the hospital, they will find all they should of reconciliation, fulfillment and meaning as they go through the last part of their lives.<sup>79</sup>

#### 8.6 How Can the Dying of Members of a Church Community Facilitate the Spiritual Growth of the Members in the Congregation?

Once a member of a church becomes terminally ill and members of the congregation could be included in the caring and the support for the family, then suddenly, death is no longer that which happens to other people; it becomes very real and very close. The community needs the dying to make it think of eternal issues and to make it listen and give to others, to re-evaluate the meaning and purpose of their lives, and if necessary to change their lifestyle.

This will also provide an opportunity to prepare the congregation for the crisis of terminal illness and death, which will build a spiritual reserve for the future. The parishioners may be given the opportunity to gain insight into their own attitudes, fears and

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<sup>78</sup>L.L.Th. Brands, In de Schaduw van de Dood (Hilversum: Gooi en Sticht, 1974), p. 127.

<sup>79</sup>Cicely Saunders, "Watch with me," Nursing Times (November 26, 1965)

beliefs, to the end that when they become personally faced with the crisis of death, they may be more readily prepared to deal with their anxieties and their doubts in an open and creative atmosphere. For the pastor to make this opportunity for true Christian growth possible is to show that this faith is a declaration about present reality, not only a promise of something beyond death. And to realize this fact is to comprehend that every believing Christian is already a partaker in the eternal life of God, of whom Christ is the first fruits.<sup>80</sup>

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<sup>80</sup>Carlozzi, Death and Contemporary Man, pp. 63-64.

## CHAPTER 9

### CONCLUSION

#### 9.1 Important Findings and Implications

1. I found that the pastoral care of the terminally ill patient (adult as well as child) often is not only inadequate but it is sadly neglected. By following the general trend of isolating patients the pastor and the Church are responsible for additional pain and anguish.

2. The family of the terminally ill patient is ignored in the comprehensive care plan. Being concerned about the family, the terminally ill patient suffers unnecessary turmoil. Patients who were in a position to experience that their families were taken care of and who could anticipate that this will continue after her/his death experienced more inner peace and used their energy in constructive ways.

3. Many pastors find it difficult to communicate with children. As a result terminally ill children are seldom visited by a pastor.

4. Growth can only take place if the patient finds her/himself in a therapeutic community which facilitates her/his growth. Growth could be on an interpersonal or an intrapersonal or spiritual level.

5. People who find it difficult to face death, trust and to give up life are people who never really trusted in the first place. If one has something to live for, in a paradoxical way it gives meaning to one's life. Because one has faith in the meaning of life, then somehow it is easier to accept the uncertainty of dying. "My life is all right, therefore I will accept death, although it's sad to leave it. Since life has meaning death must have meaning too!" It is where life has been undermined and one's trust in either people or oneself or both is undermined, that people find it hard to die. Often when a marriage, for instance, is broken up, this has already shaken a person's feelings of security and one's feeling of trust. Thus, it will be much more difficult to work through one's impending death.

6. Persons who have difficulties in handling every day problems very often have difficulty in coping with the fact of their impending death.

7. The trained hospital chaplain can render invaluable services to parish pastors in helping them through clinical experience to grow in skills. Frequently they need support and consultation on their pastoral care. Educational programs for clergy could be developed.

8. There is a need for groups in the hospital situation. By initiating growth groups the pastor can use her/his time and skills more constructively.

9. Non-verbal communication is extremely important in the work with terminally ill patients.



10. We criticize the medical profession for some of the things they haven't learned in their training, but there is also very serious omissions in the training of theological students. No pastor is going to avoid the hospital and suffering and dying in her/his ministry. The care of the dying should be included in the curriculum. It is a must! There are several schools of theology where each student is required to work in a C.P.E. program for eight weeks before they begin their final year of study.

11. The pastor has to implement and use the latent resources available in the congregation.

12. The pastor cannot function separate from the medical team. Interprofessional training and discussions are very important.

#### 9.2 Recommendations For Further Research

1. It is important to determine whether patients would prefer to work with the official hospital chaplain or whether they prefer their own parish minister. An emperical study must be done. If they are willing to accept the hospital chaplain in lieu of their parish pastor it could save the pastor an enormous amount of energy and time which could be spent more profitably in the parish, rather than traveling to and from the hospital.

2. More study and research concerning the use and effectiveness of non-verbal communication in a hospital is necessary.

3. A careful study and analysis of the therapeutic value of groups in the hospital could be helpful in determining where groups could be used most effectively.

4. An empirical study to determine the spiritual needs of the terminally ill patient and the family will help the church to minister in a more adequate way to their needs.

5. It is important to do an empirical study to determine the validity of Elizabeth Kübler Ross's statement that religious patients seemed to differ little from those without a religion, to determine whether faith and religion becomes (more) important during the terminal phase of one's life.

6. A study to determine how pastors feel about their ministry to the terminally ill and whether they are sufficiently equipped to engage in such care would be useful.

## APPENDICES

## APPENDIX A

### HOW TO HELP A PERSON IN CRISIS<sup>1</sup>

Here is a method which crisis counselors have found effective; it is a useful tool for helping yourself, a friend, or anyone else who has asked for your help. The method\* consists of doing three things:

#### A—ACHIEVING A RELATIONSHIP

- Listen with caring to what the person is feeling and experiencing ("Listening love"). "Check out" what you understand him to be saying to see if you're on his wavelength.
- Let him experience your warmth and concern.
- Ask him to tell you about the crisis—when it started, how it developed, how he feels about it.
- Let him know you'd like to work together in finding something that can be done to help—preferably to help him help himself.

#### B—BOIL DOWN THE PROBLEM

- Help him sort out the pieces of the problem he is facing.
- Help him to separate those parts about which he can do something from those about which he can do nothing. (No use wasting energy on the latter.)
- Encourage him to describe what he has tried (No use repeating those things that haven't worked.)
- Encourage him to describe or discover other possible solutions.
- Help him examine each of these in terms of their probable consequences—"What will probably happen if you . . . ?"
- Help him to decide on which of the various alternatives he wants to try now.

#### C—CHALLENGE HIM TO ACT

- Encourage him to plan just how he will begin doing what he has decided to do; plan should be realistic, with achievable goals.

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<sup>1</sup>Howard J. Clinebell, Jr.

\*This method is adapted from Warren Jones' ABC method of crisis intervention.

- Encourage him to commit himself to doing this, beginning soon and at an agreed-upon time.
- If he has resistances to beginning to act on his problem, help him discuss and resolve these feelings.
- Assure him that you will continue to be available to him as he tries to act in some constructive way; support him with realistic hope.
- Don't agree to do anything for him that he can do for himself if he has to. The personality is like a muscle—exercise!
- Point out that as he begins to do something, however small, about his situation, he'll probably start to feel better—less depressed, more hopeful.
- Have him phone you before you see him again to let you know how his action plan worked; make a date to see him again soon.
- Help him find the resources to cope—spiritual, interpersonal, inner.

In subsequent meetings, have him describe what happened, affirm him for his successes in implementing his action plan (however small these successes), help him re-think his action goals (What's the next step?), repeat those parts of B and C which are necessary to help him continue coping.

How this method works. Eric Berne's system of helping people holds that there are three parts to everyone's personality—PARENT side, CHILD side, and ADULT side. This method helps a person activate his ADULT side (which can enable him to cope with his situation), at a time when his CHILD is dominating his personality (and preventing him from coping).

## APPENDIX B

### HOW TO SET UP AND LEAD A GRIEF RECOVERY GROUP<sup>1</sup>

Nature and importance of the group: A grief recovery group is one of the most useful types of growth groups. Such a group is a self-help, or more accurately, a mutual-help group, in which people who have suffered a significant loss of any kind can experience the healing which can occur in a small sharing and caring group. Few if any types of growth groups can contribute more to the enhancement of the spiritual and mental health of persons than an effective grief group. A loss or the threat of a loss is a key cause in all crises. Almost everybody is carrying some burden or loss. Unless people have the kind of help in dealing with their grief which is available in a sharing group, many will not experience the healing of their grief wounds.

The place of a grief group in a church or agency: A church or temple is a natural and strategic place to have a grief group, since religious leaders are usually involved in funerals and in the process of loss and grief that precedes and follows these. Grief groups are relatively easy to start and lead, and usually are helpful to the participants in a variety of ways. Such a group is an excellent way of implementing the biblical truth which holds that it is blessed to mourn and the call to bear each other's burdens. Grief groups are also a useful and important part of the program of any counseling or helping agency, since many of those who come with marital and other problems are also suffering unhealed grief wounds. (Often they are unaware of the connection between their losses and the onset of their problem.)

Two models of groups: Ad hoc groups, set up for a limited period of weeks—usually from six to ten—have certain advantages. Some people will commit themselves to a time-limited group who will not come to a long-term or continuing group. The terminus of the group often stimulates participants to work more productively within the time limits. (A group can re-contract at the end of the agreed-upon time, if there is common desire to extend the length of the group.) However, some churches and social agencies have found that an ongoing, open-ended grief group, which people can join when they need it, and leave when they no longer feel this need, is a valuable resource.

Mixed or specialized group: Persons who have experienced a similar type of loss (e.g., the death of a loved one) tend to become a group

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<sup>1</sup>Howard J. Clinebell, Jr.

relatively quickly because they can identify with each other's losses. They can understand and help each other, both with painful feelings and the practical realities of coping, because they have been through similar experiences. These are some of the advantages of specialized grief groups composed of entirely those persons who have been through divorce, or the loss of jobs, or losses from surgery or accidents, or the loss of loved ones by death. But, grief groups composed of persons with a variety of losses are also effective. They allow persons to discover the common core of any significant loss experience which is very similar in different types of losses. In a small church or agency it may be most feasible to have a mixed grief group.

Purpose of a grief group: The purpose (which should be spelled out in the invitation or publicity) is to help persons who have experienced losses deal constructively with the feelings and practical problems which result and to help each other by sharing in a small group. Some groups have a second purpose—to discover ways in which they can reach out to others in a church or community who also are going through losses. The discovery that one's painful experiences are potential resources for helping others who are experiencing similar losses, is an important growth discovery which occurs in such a group. The purposes of any group should be described in terms of the theology or philosophy of the church or agency which sponsors the group.

Recruiting a group: In a congregation, a group can be started simply by the minister's inviting those who have experienced a loss within the past few years to join the group. Personal invitations to the persons he or she knows, and a general invitation in the church's bulletin or newsletter to reach others, usually results in enough persons to start a group. In an agency setting clients can be referred to a group or advised of the availability of a group (e.g., a Divorce Growth Group).

Size of group: For effective sharing, a group should not be larger than 12 or smaller than 3, plus the leader-facilitator.

Leader: The role of the leader is to recruit and convene the group, to help the group develop a clear, mutually acceptable contract (usually spelled out in broad outline in the publicity), and to facilitate the process of sharing on a meaningful level—the level where persons are experiencing pain and for facing practical problems. Any clergyperson who has had clinical training or supervised group counseling training, or who is fortunate enough to be an open, warm and congruent person, can facilitate a grief group. It is an advantage for the leader to have been through a significant loss. Some lay persons who have been through grief groups and other growth group experiences discover that they have natural aptitudes as growth group facilitators. Such persons should be offered opportunities for additional training and encouraged to co-lead a grief group with the

minister. Mental health professionals who are trained in small group methods can be invited to lead grief groups or help train leaders for such groups. It is important for any leader to be open about his/her own losses and pain.

Stages of recovery from bereavement: There are usually at least four stages in the process by which a grief wound heals. Stage 1 - Shock and Numbness: The person most needs support, caring and nurture. Stage 2 - Working through Feelings: The whole range of human feelings can be experienced, but feelings of guilt, resentment, anger, loss, remorse, emptiness, loneliness, release and relief (if there has been a long illness or an unhappy relationship) are frequently present. Expressing and experiencing the painful feelings, whatever they are, is essential to healing the grief wound! Stage 3 - Unlearning old patterns and relearning new ones: Letting go of whatever one has lost and of the satisfactions associated with that person or thing is usually painful, requiring unlearning countless patterns of responding. Letting go of the person or thing releases this energy to be reinvested in new relationships and activities which can replace some of the lost satisfactions. Stage 4 - Reentry: This involved pulling one's life together without the lost person or thing, rejoining the ongoing stream of life and responsibilities, and rebuilding one's ways of satisfying basic needs. If a person moves through these four stages successfully, his or her inner strength and resources for coping with future losses will probably be increased by the experience. This is what is meant by the growth opportunity in a grief experience.

The role of grief groups in these stages: In Stage 1, a group or members from it can surround a person with support and express caring in such tangible ways as being present, listening, and bringing food. The first stage usually goes on until after the funeral, even though the person begins to do the "grief work" of Stage 2. At least a year, or longer, is usually required to work through and resolve the enormous feelings associated with a major loss. An ongoing grief group can be of decisive help, as can the members of a grief team of a minister/counselor. A 5 to 10 session grief group can facilitate the process of moving ahead in Stages 2, 3 and 4, which overlap and intertwine. Any grief group can give two kinds of mutual help—encouragement and help in dealing with painful feelings, and reality testing as one deals with the decisions and practical changes which result from any major loss.

A structured grief group: One of the easiest ways to begin and lead a grief group is to use chapters of a book as the outline of topics, week by week. Participants should be asked to agree at the outset to read one or two chapters between each session. The leader can begin a session by asking: "How did the ideas in this week's chapter relate to your own experience of loss?" This usually opens the door for vigorous mutually-helpful sharing on a personal level. (See resources at bottom of sheet for books and cassettes to use in groups.)



The wound that doesn't heal: Occasionally, one encounters a person whose grief wound isn't healing normally. In most cases this is a person whose wound is infected by unfaced guilt, remorse, resentment, and ambivalence toward the lost person which has been too painful to face and work through. The God-given forces of healing and growth which are available in persons and their relationships are blocked. An effective grief group or counseling relationship often releases the person to grieve, let go of the loss, and experience healing. If this does not happen, it is important to encourage the person to see a competent psychotherapist. Some signs that may indicate the presence of an unhealed grief would include: Inappropriate and undiminished grief; little or no grief; continuing or increasing withdrawal from relationships; prolonger or undiminishing hostility; pretending the loss is not real; psychosomatic illness; continuing undiminished depression; personality changes, sudden or gradual; retreat into excessive use of drugs, alcohol, or other pain-deadeners.

The stakes are high: Many of us who do not have obvious symptoms of unhealed grief such as those listed above carry partially healed wounds even though we function adequately in our relationships and work. The price of partially healed wounds is diminished creativity, feelings of aliveness, and capacity to enjoy life, and the waste of life energies which could be put to constructive use in other areas of our lives and relationships.

A spiritual growth opportunity: Every major loss, like every crisis, is potentially a spiritual growth opportunity. A grief experience confronts us with the need to examine our values, to look at the adequacy of our personal faith or philosophy of life, and to make needed changes in our lifestyle and values. A grief group provides a community of caring within which such spiritual growth work can best take place. A group can enable all of us to find the courage to risk looking at the brevity and frailty of our lives, and to seek ways of putting these facts of our finitude into the context of a larger meaning which transcends our individual lives. The leader of a grief group is thus a spiritual growth facilitator. By asking questions such as, "How does this experience relate to what you believe is important?" or "How does this loss relate to your personal faith?" or simply "What have you learned from this experience?" the leader often can open opportunities for spiritual exploration and discovery.

#### RESOURCES FOR USE IN GRIEF GROUPS (For the leader-facilitator)

Clinebell, H.J., Jr. The People Dynamic: Changing Self and Society Through Growth Groups (N.Y.: Harper and Row, 1973). The principles of setting up and leading growth groups, including grief groups.

Leslie, Robert. Sharing Groups in the Church (Nashville: Abingdon Press). Describes different types of sharing groups and how to lead them.

For the leader and the group members

Clinebell, H.J., Jr. "A Grief Recovery Group" (Course 2B), "The Crisis of Divorce—Growth Opportunities" (Course 3B). Growth Counseling—Coping Constructively with Crises (Nashville: Abingdon Press, 1974). A do-it-yourself set of courses on grief groups and divorce groups, including segments from grief groups and divorce groups.

Westberg, Granger. Good Grief (Rock Island, Ill.: Augustana, 1962). A paperback summarizing the insights about coping with the stages of recovery from grief; can be used as a resource in a grief group.

Jackson, Edgar. Understanding Grief, Its Roots, Dynamics and Treatment (Nashville: Abingdon, 1957). A comprehensive discussion of grief and the process of recovering from it.

Jackson, Edgar. You and Your Grief (Manhasset, N.Y.: Channel Press, 1961). A guide to the process of recovery from grief.

Caine, Lynne. Widow (New York: William Morrow and Company, 1974).

Kübler-Ross, Elizabeth. On Death and Dying (New York: The Macmillan Company, 1969). A paperback book for use in growth groups on grief and dying.

Lewis, C.S. A Grief Observed (New York: Seabury Press, 1961). His moving account of Lewis' response to the death of his wife.

## APPENDIX C

### PATIENT EVALUATION

	Age	Case Note Number:
Name of Patient (Surname first in capitals)	Date of Admission	Date of Death
Surname of Key Person	First Name	
Address	Telephone	
Relationship to Patient	O.P.	Yes/No
Do you think key person would object to follow up?	Yes/No/Not known	
Staff Member(s) most closely involved:		
Other Family Members in need of help:		
Comments: (include details of help already being given):		

Signed:

Questionnaire: (Ring one item in each section. Leave blank if not known.)

\_\_\_\_\_ Tick here if key person is not well enough known to enable these questions to be answered.

A. Children under  
14 at home

- 0. None
- 1. One
- 2. Two
- 3. Three
- 4. Four
- 5. Five or more

B. Occupation of principal  
wage earner of key  
person's family

- 1. Profes. & Exec.
- 2. Semi-profes.
- 3. Office & clerical
- 4. Skilled manual
- 5. Semi-skilled manual
- 6. Unskilled manual

C. Anticipated  
Employment of  
K.P. outside home

- 0. Works F/T
- 1. Works P/T
- 3. Retired
- 4. Housewife only
- 5. Unemployed

D.  
Clinging  
or Pining

1. Never
2. Seldom
3. Moderate
4. Frequent
5. Constant
6. Constant &  
Intense

E.  
Anger

1. None (or normal)
2. Mild irritation
3. Moderate - occasional  
outbursts
4. Severe - spoiling  
relationships
5. Extreme - always  
bitter

F.  
Self Reproach

1. None
2. Mild - vague &  
general
3. Moderate - some  
clear self  
reproach
4. Severe - Preoc.  
self blame
5. Extreme - major  
problem

G.  
Relationship Now

0. Close intimate relationship  
with another
2. Warm supportive family  
permitting expression  
of feeling
3. Family supportive but  
live at distance
4. Doubtful
5. None of these

H.  
How will Key Person cope?\*

1. Well. Normal grief and recovery  
without special help.
2. Fair, probably get by without  
special help.
3. Doubtful, may need special help.
4. Badly, requires special help.
5. Very badly, requires urgent help.

\*All scoring 4-5 on H will be  
followed up.

(Used at St. Christopher's Hospice in London.)

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